Cost Containment in Long-Term Care: Options and Issues in State Program Design

A Synthesis of Findings from Health Services Research and Demonstration Projects

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SYNTHESIS AND DISSEMINATION OF
HEALTH SERVICES RESEARCH FOR STATE AND MUNICIPAL HEALTH LEADERS

Cost Containment in Long Term Care: Options and Issues in State Program Design

A Synthesis of Findings From Health Services
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Lewin and Associates, Inc.
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PREFACE

This synthesis was prepared by Lewin and Associates under contract to the National Center for Health Services Research (NCHSR) as part of an effort to assist state and local officials in applying the results of health services research to current issues in health programs. Supervised by the NCHSR User Liaison Program, Lewin and Associates has worked with officials in the states of Florida, Illinois and Michigan to identify priority concerns and prepare written syntheses of research relevant to the decisions officials are confronting in these areas. Long term care was the first area identified on this concensus. This document Cost Containment in Long Term Care: Options and Issues in State Program Design and two accompanying volumes Expanding Long Term Care Efforts: Options and Issues in State Program Design and Long Term Care: Options and Issues in State Programs: A Bibliography address two aspects of the long term care issue and, while written based upon discussions with officials in Florida, Illinois, and Michigan, are applicable to other states as well.

The National Center for Health Services Research has also contracted with the Western Interstate Commission for Higher Education (WICHE) to prepare two syntheses on other aspects of long term care, A Synthesis of Research on Client Needs Assessment and Quality Assurance Programs in Long Term Care by Bettina Kurowski and Linda Breed, and A Synthesis of Research on Nursing Home Reimbursement by Eileen Tynan, Daniel Holub and Robert Schlenker. These syntheses were written by members of the staff of the Center for Health Services Research, University of Colorado, after discussions with health officials in Colorado, Wyoming, and the city of Denver.

The Lewin and WICHE contracts with NCHSR also specify that a series of workshops on long term care will be held for interested state and local officials in the states with which the contractors have worked as well as for interested officials in other states.

Both the syntheses and the workshops are a part of an effort by the National Center for Health Services Research to make health services research more accessible and relevant to state and local officials. In order to improve these efforts, NCHSR welcomes the comments and suggestions of people in the states. All communications should be addressed to:

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This effort has benefited enormously from the direction and assistance provided by the National Center for Health Services Research Project Officer, Mr. Robert Fordham, his associate, Ms. Nancy Blustein, and his reviewers, Drs. Christine Bishop and Alan Rosenfeld, of Brandeis University, Dr. Mark Meiners, of the National Center for Health Services Research, and Ms. Kathleen Cook, of the New York State Department of Health.

The interpretation of the research findings are those of the authors and do not necessarily represent the views of the National Center for Health Services Research or the reviewers.

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SUMMARY

The problems of the elderly have become major issues for state and local policy-makers. During the 1960's, as the problem of this group were brought to the public's attention, new programs were developed at the federal, state and local levels. These have become very costly, yet surveys suggest that there are still extensive unmet needs within this group. This has generated conflicting pressures on state officials to both control the costs of these programs and expand the number of people being served and the range of services provided.

This report is designed to assist states exploring policy options which address the first of these pressures. It does this by reviewing the implications for the design of programs to reduce or control the financial burden of long term care activities. While this review did not identify one clear direction for state efforts, the analysis can help states assess the feasibility of alternative options by clarifying their impact on who will be affected and how and by assessing both the fiscal and personal consequences of pursuing specific activities.

The report is designed to be policy oriented. Rather than merely summarizing the research, it outlines options that are being discussed by states for controlling the costs of long term care program and applies the research to key questions about each option. A companion report entitled Expanding Long Term Care Efforts: Options and Issues in State Program Design examines options which are being discussed for expanding programs to address the most severe unmet needs. Taken together, the reports present research which may help state officials resolve conflicting pressures to both control the costs of long term care services and expand the range and delivery of them.

In the course of reviewing the research, several conclusions emerged that provide a context for examining all of the options discussed. These are:

- Most of the elderly do not and will not need publicly funded long term care services. For those using services, most will not use them until late in life.

- Most long term care services are provided by family and friends or are purchased through private resources, despite substantial and growing public subsidies.

- An individual's level of impairment is not a sufficient predictor of whether he or she will use publicly funded services. Other important factors are whether an individual is currently married or has other close family and the financial resources he or she possesses.

- Demographic trends indicate that if the current structure of long term care is continued, demand and costs will continue to increase.

Controlling the Financial Burden of Long Term Care Programs

A major goal of state health policy is to control the financial burden imposed by long term care programs. This goal can be interpreted in several ways. It might mean seeking to moderate future growth of costs in these programs, or seeking to provide a more appropriate mix of services at lower cost, reducing the current levels of expenditure and service, or shifting support for care to other units of government or to private resource. Implications under each of these interpretations were considered.

Five options to realize this goal were explored.

Shifting Clients from Institutional Settings to Community-Based Settings

This strategy would be achieved by shifting those pople in nursing homes who do not need the full range of services provided by these facilities to a community setting where supportive services are available. The research suggests that while overall costs might not be substantially reduced, the costs incurred by the state may decline. Cost savings may accrue from keeping emptied nursing home beds vacant or from filling them with clients from more costly care settings, such as hospitals. Program management controls would have to be established to assure this occured. In addition, some savings may occur from shifting financial responsibility for the deinstitutionalized from the states to the federal government.

The feasibility of this strategy is dependent upon several factors. First, an adequate supply of housing must be available. Many of those institutionalized lose their homes immediately before or after institutional placement, and as a result would have no homes to return to if they were discharged. To meet this need, federal or state housing assistance would probably be required. Second, while the deinstitutionalized population would have only a limited need for supportive medical services, they are likely to require both personal and housekeeping services and have little access to informal sources of such services through family and friends. Those needs would have to be met. Third, care must be taken that the shock of deinstitutionalization does not adversely affect the health status of the elderly.

Diverting Clients at the Time of Institutionalization

One strategy for reducing the financial burden of long term care programs is to divert clients from nursing homes at the time that they try to enter them. This would be achieved by denying nursing home care to Medicaid eligibles who can be appropriately cared for in the community.

This is a promising cost saving strategy, it may be established as a policy which diverts clients to community care only when its costs to the state are less than that of nursing home care. The successful implementation of this strategy, however, depends on several factors. These include:

- Availablility of community-based services.

- Acceptance of the screening agency of the focus of the program in deterring unneeded institutionalization rather than expansion of the use of community services to others who are not seeking institutional care.

- Effective assessment tools and quality assurance programs that assure that Medicaid eligibles are not denied needed care.

- Legal authority to require those who are not currently Medicaid eligible but will likely soon become eligible to submit to screening at the time they seek entry into an institution.

Increasing Preventive Efforts so as to Reduce the Long Run Need for Institutionalization

This strategy is based on a policy of promoting long term preventive services, such as home care, housing, day care, and nutrition programs in order to reduce the future need for institutional services. This strategy is unlikely to promote cost savings for three reasons:

- First, while it is plausible that providing these services before clients consider institutionalization will reduce institutionalization rates in the future, this has not yet been demonstrated.

- Second, these services are often used for longer lengths of time than institutional care and their total cost per client may not be lower.

- Third, the risk factors associated with institutional placement are not clearly enough defined to allow for the targeting of prevention services to only those people at high risk of institutionalization. As a result, under this strategy, the states are likely to increase their service base and increase their aggregate costs.

Increase the Share of Expenses Assumed by Families

Under this strategy, the states would reduce their financial responsibilities for long term care programs by increasing the share of expenses assumed by the elderly and their families. The cost saving potential of this strategy is unknown. Families are already providing the bulk of long term care services. Many of those using publicly funded services don't have spouses or other sources of support. It may, therefore, be impossible to obtain additional funds or services from families.

Before this is conclusively determined, however, several policies merit further exploration. They are:

- Creating financial incentives for families to keep their relatives out of nursing homes.

- Providing services which increase the ability of families to keep their relatives out of nursing homes.

- Establishing policies directed at preventing asset-transfer.

It may also be possible to implement such policy managerially by orienting case workers to seek the maximum continued involvement and support from families and neighbors in providing informal, unreimbursed services.

Reducing the Range of Services Funded by the State

Some states have considered eliminating intermediate care (ICF) as a benefit under Medicaid as a means of reducing costs to the state. This would have significant social implications and would not lead to cost savings. By abolishing ICF services without replacing the care delivered by these institutions with community or home-based services, significant hardships may be imposed on the people who have traditionally used this service. In addition, aggregate costs may increase as poeple who could be cared for in ICFs are forced to obtain care in more expensive SNFs or hospitals.

Even if non-institutional services are provided in lieu of ICFs, this strategy has several drawbacks. Most notably, there is a core group of ICF residents who cannot be cared for in the community. An abolishment of ICF level care would either cause them to suffer significant hardships or to seek care from SNFs or hospitals. A more moderate diversion strategy that leaves open the placement in intermediate care facilties appears more appropriate.

Some Major Unanswered Questions

A review of long term care literature relevant to this synthesis disclosed a large number of unanswered questions and limited information upon which to analyze policy. On the basis of this review, the following areas have been identified requiring more research:

- Factors that influence the use of publicly funded services, and the substitution of private services by public services, including the interaction of risk determinants like levels of impairment, social supports, and income, and the factors influencing family decisions to seek institutionalization or transfer assets.

- Information on patient transfer patterns and ways to encourage transfers from unnecessarily high levels of care to lower levels of care.

- More analysis of the relative costliness of service in different settings and the reasons for variations in program costs.

- An analysis of the impact of future trends in health manpower on the delivery of long term care services.

- Analysis of administrative and organizational factors that enable a program to succeed in one area while one with similar goals and overall strategy fails in another.

INTRODUCTION

WHAT THIS DOCUMENT IS INTENDED TO DO

The problems of the elderly have become major issues for state and local policy-makers. During the 1960's, as the problems of this group were brought to the public's attention, new programs were developed at the federal, state and local levels. These have become very costly, yet surveys suggest that there are still extensive unmet needs within this group. This has generated conflicting pressures on state officials to both control the costs of these programs and expand the number of people being served and the range of services provided.

Services directed at the elderly, particularly those with chronic medical conditions or physical or mental impairments, are usually placed into a general category called long term care. The boundaries of this category are ambiguous, but as used in this report the term long term care refers to any service designed to assist chronically ill, disabled, or socially impaired elderly people over an extended period of time. These services may range from skilled 24-hour continuous nursing care to periodic housekeeping assistance.*

The issues that need to be dealt with in the long term care area are complex. The conflict between the goals of cost control and service expansion is one source of this complexity. States bear large financial burdens as a result of their current long term care programs, but are also under considerable pressure to fill the gaps in their programs by providing alternatives to the institutional services that are currently at the center of their long term care efforts.

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* While mentally or physically impaired people of all ages may require long term care, the long term care programs that are discussed in this document are only those which are particularly relevant to people over the age of 65.

A second source of complexity is the diversity of the needs of the elderly. The problems faced by the aged are not all, or even primarily medical, but often they are addressed through medical programs because this is where funding has been available. Financing has determined service patterns and created major distortions in the mix of services and perceptions of the elderly's needs. These, in turn, make dealing with these problems more difficult.

A third factor adding to the complexity of these issues is the way in which programs have been developed independently of one another. This has led to conflicts in definitions, eligibility criteria, provider certification standards, and a lack of linkages among complementary programs. There is no system of long term care.

Those involved in state health policy -- the Governors' offices, social service departments, aging units, budget bureaus, legislatures -- are currently trying to develop more effective programs to meet long term care needs. This report is designed to assist in that process by reviewing the available research on long term care and drawing from the research its implications for designing programs for the elderly. While our review did not identify one clear direction for state efforts, the analysis presented here can help states assess the feasibility of alternative options by examining their impact on who will be affected and how, and by assessing both the fiscal and personal consequences of pursuing specific activities.

The report is designed to be policy oriented. Rather than simply summarize the research by service category, we have described major options for addressing long term care needs that are being discussed within states. We then tried to use the research to answer the central questions about each option.

Thus, one goal for state policy is to reduce the financial burden of long term care programs, or at least to control the growth of this burden. This document looks at this goal and five options that have been proposed for achieving it. These include suggestions for reducing the size of the institutionalized population and ways to increase the level of support obtained from families. The assumptions underlying alternative options are identified and the available research is used to assess whether those assumptions are reasonable.

A separate volume presents a similar analysis of the options for expanding long term care programs. It examines unmet needs of the elderly population and strategies which may satisfy these needs.

In the course of reviewing the research, several conclusions emerged that provide a context for examining all of the strategies discussed. These are:

- Most of the elderly do not and will not need publicly funded long term care services. For those using services, most will not use them until they are seventy-five or older.[46,65,92,128]

- Long term care services can be provided by family and friends or can be purchased from private agencies or individuals. The cost of purchased services may either be borne by recipients and their families, by government, by philanthropy, or shared among these groups. Surveys of The elderly population indicate that most long term care services are provided by family and friends or are purchased through private resources, despite substantial and growing public subsidies. (See pages 66-69)

- An individual's need for services, as assessed by the extent of regular medical supervision he or she requires, or his or her inability to run a household or personally care for him or herself,* is not a sufficient predictor of whether he or she will use publicly funded services. Other important factors are whether an individual is currently married or has other close family and the financial resources he or she possesses. Public services appear to be used only as a fall back and as a last resort.[67] (Also see pages 60-61)

- Demographic trends indicate that if the current structure of long term care is continued, demand and costs will continue to increase. There are several factors contributing to this:

  -- The over 65 year old population is becoming an increasing percentage of the country's total population.

  -- Life expectancy is rising, leading to longer periods of old age.

  -- The difference in life expectancy for men and women is widening, leaving a larger number of women alone in their old age.[123]

- While controlling the costs of long term care programs is frequently discussed, this phrase has two very different meanings. Sometimes it refers to the total costs of care, regardless of who bears them. In other cases, it refers to

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* These assessments can be quantified. The results of an assessment is often referred to as a measure of functional status and will be referred to by these terms in the rest of this report.

the costs to one specific party (such as an individual client, the state, or the federal government) and in this latter case, cost control may mean shifting costs from one party to another. This distinction is critical when analyzing the impact of specific options on costs.

The reader familiar with the long term care field may wish to go directly to the discussion of the cost containment options provided in Chapter Two. Those who want more background on long term care -- how it is organized and financed, who it serves -- should read Chapter One in which an overview of current patterns of care is presented.

The report has several other sections. Chapter Three presents recommendations for future research which is needed for state and local policy-making. An appendix provides a list of references and a discussion of how the research included in this report was identified and assessed. An index to the references and detailed annotations describing the most important studies are included in a separate volume, Long Term Care: Options and Issues in State Program Design: A Bibliography.

CHAPTER ONE
HOW LONG TERM CARE IS CURRENTLY ORGANIZED

To understand the options available to state policy-makers in restructuring their long term care programs, it is necessary to understand how the current system of long term care is organized and financed. This chapter briefly reviews this organization and the role of state governments in managing the system. It also discusses the role played by private resources in funding long term care and presents several critical questions for state governments to consider as they evaluate their options.

What are the Sources of Government Support for Long Term Care?

The current system of financing long term care is embodied in a series of categorical programs. None of these was developed primarily to address long term care needs, but they have been adapted to this end as long term care problems have grown in prominence. Furthermore, they were developed independently and at different times and, as a result, have diverse financing structures, target populations and eligibility requirements.

There are five programs or groups of programs which are jointly funded by the federal and state governments or which have a large degree of state administration:

- Medicaid (Title XIX). This is the major source of government funding for long term care. Care in skilled nursing facilities (SNF) is a mandated basic service. Care in intermediate care facilities (ICF) is an optional service, but one covered by every participating state. Home health care services became a covered service in every participating

state in 1970. While expenditures are miniscule compared with those for nursing home care, they have been increasing rapidly. (In 1975, $4.2 bilion was spent for nursing home care; $113 million for home health care. By 1977, home health expenditures under Medicaid had more than doubled to a total of $241 million.) The program is funded on formula of federal-state cost sharing.

- Title XX Social Services. Title XX provides funds to states for social services for recipients of income-tested cash payment programs such as Aid to Families with Dependent Children. These services can include chore/homemaker services, adult day care and adult foster care. The Congressional Budget Office estimated that in 1976, only $66 million was spent on these services for the disabled. While the program is funded on a formula of federal-state cost sharing, the total federal share is capped. Many states now spend more than their ceiling and, therefore, provide all additional dollars.

- Older American Act Programs, Grants for States and Community Programs on Aging, (Title III). This title provides states with funds for nutrition and social services for the elderly. There are no means tests for recipients, but programs are usually located in low income areas. By themselves, these programs cannot meet all long term care needs of an individual, but may provide specific services.

- Rehabilitation Programs. Programs such as Vocational Rehabilitation, can serve as another source of funds for the long term treatment of the chronically ill elderly, although they are most often directed at younger populations.

- Housing Services. An extensive portion of the public and subsidized housing programs are targeted for specially adapted or congregate housing for the elderly.

There are other types of programs primarily administered by the federal government over which the states have little control:

- Medicare (Title XVIII). The health insurance program for the aged, Medicare, is geared to acute care, rather than chronic or long term care. It has limited skilled nursing facility and home health benefits that must be preceeded by an acute spell of illness. In 1975, expenditures for these programs were $285 million and $199 million respectively. Home health care services under Medicare have been growing rapidly. By 1977 estimates indicated $433 million was spent on home care under the Medicare program. This represents an increase over the 1975 level equal to 47% annually.[101]

- Veteran's Administration. The VA provides several types of long term care for veterans. These include institutional care in ICFs and domiciliary care facilities (that provide room, board and some personal services but no medical services), contracted nursing care, and some home health care. The VA also provides cash allowances to disabled pensioners which are intended to allow them to purchase services at home. It is not known, however, whether these funds are used for that purpose.

- Supplemental Security Income (SSI). SSI is a cash grant program to the needy aged, blind and disabled, with a minimum federal payment that can be supplemented by the state. These

grants are provided on the basis of income and eligiblity criteria. They are not payments for specific services. For those who are living in domiciliary care facilities, it pays for their care plus a modest amount for discretionary funds. SSI recipients are also eligible for Medicaid and Title XX programs.

In the long term care field, the concept of a continuum of care is often advocated. By this is meant having available within the community a range of services geared to meet different service needs and intensities of need. The range of elements that have been suggested as components of this continuum are presented in Exhibit 1, which also describes the role each service plays and the extent to which it has been researched.

In principle, the collection of the government financing programs described above might be structured to provide for a continuum of care. At the present time, however, most government spending for long term care has been for institutional services, and Medicaid has been the primary funding source. For all public programs, support for institutional care accounted for approximately 90% of 1975 spending; Medicaid contributed an estimated 75% of all government spending in this same year.[3]

How Do These Services Relate to the Needs of the Elderly?

One of the major problems in the long term care field is defining an individual's need for services. One approach to measuring this need is to assess an individual along three dimensions:

- The extent to which he or she needs continuous medical care or close medical supervision.

THE LONG TERM CARE CONTINUUM

Service or Provider Category	Role in the Continuum	Extent Studied or Research Available
Skilled Nursing Facility Continuous skilled nursing care or other skilled rehabilitative care provided in a residential facility on a 24 hour a day basis; requiring the care of a skilled nurse or under the supervision of a skilled nurse or other skilled rehabilitation provider.	Necessary for people in need of continuous intense services; especially those in need of nursing care with rehabilitative therapy.	Considerable research available profiling client population and assessing cost effectiveness of program vis a vis non-institutional services (especially home health).
Intermediate Care Facility Health related services that can only be offered in an institutional setting which are below those offered in a hospital or SNF, but above that of room and board. In many states, several levels of ICF care have been established.	Viewed as critical for those who are chronically ill and incapable of independent living.	Considerable research available profiling client population and assessing cost effectiveness of program in comparison to non-institutional services (especially home health).
Domiciliary Facility A residential institution for people not in need of health related services but in need of personal assistance, such as bathing, grooming dressing, eating, etc.	Critical for people who do not need intense medical care but are nevertheless unable to maintain an independent lifestyle and need the constant services of others; may be replaced by congregate housing.	Some research available on client population. Often overlooked by cost effectiveness research.
Congregate Housing A group living environment which promotes independent living by supplying supportive medical and social services either directly or through referral to elderly people who are in good health despite financial or social impairments.	Viewed as a necessary service to prevent elderly from using medically oriented facilities unnecessarily. Predominantly a long term prevention technique as elderly tend to enter these facilities in the early part of their old age and remain in them throughout their old age.	Considerable research available, much is advocacy literature but some studies have been undertaken to identify the program's client population and to assess its ability to postpone or prevent who institutionalization.
Home Health Care Medically oriented care for acute or chronic illness provided in the patient's home. Includes services like cleaning wounds, changing bandages, giving injections, inserting catheters.	Considered a way to provide medical care to people outside of an acute care skilled nursing or intermediate care facility. Under some circumstances may serve as a replacement to institutional care.	Extensive literature available on all aspects of home health care including needs assessment, utilization trends, cost effectiveness, and reimbursement strategies.
Chore/Homemaker Services Household services, such as shopping, cooking, and cleaning.	Seen as an essential aspect of any home care program. May be delivered in conjunction with home health care or as a separate service to those with limitations who are otherwise healthy. Under some circumstances, may serve as a replacement to institutional care.	Research is normally linked to home health care studies. Considerable advocacy literature is available which considers homemaker/chore services as separate programs.

Service or Provider Category	Role in the Continuum	Extent Studied or Research Available
Personal Care Services Personal care includes such services as bathing, dressing, and grooming provided in the participant's home.	Seen as an essential aspect of any home care program usually delivered in conjunction with home health care or chore/homemaker services and there is ambiguity in the definition of the boundaries between these services and personal care. Under some circumstances may serve as a replacement to institutional care.	Research is normally linked to home health care and chore/homemaker services.
Respite Care Short term inpatient or outpatient care delivered to an elderly person in lieu of his or her regular source of support. The program is normally designed to provide relief to relatives and friends who care for an elderly person on a regular basis.	Seen as a way to encourage families to take care of their elderly relatives by providing periodic relief from the demands of caring for an older person. It may be provided as a component of other services in the continuum. Primarily a financing issue as nursing homes, home health agencies, and private duty nurses frequently provide this service when money is available.	Little research available. Usually mentioned as part of the long term care continuum in the advocacy literature.
Meals on Wheels The delivery of inexpensive, nutritionally sound means in the participant's home. As well as providing meals to people who are unable or unlikely to cook for themselves, the program provides social contact to isolated people.	Seen as a health promotion service which also acts to prevent the isolation of the elderly with limited mobility.	Little research available. Usually mentioned as part of the long term care continuum in the advocacy literature.
Nutrition Programs Programs designed to provide inexpensive nutritionally sound meals to elderly people in congregate settings.	Seen as a health promotion service which also encourages social interaction among elderly people.	Some research available which profiles uses of the service and analyzes operational aspects of various programs.
Adult Day Care A wide variety of day care programs exist. Two major models are: Medical Model: An outpatient center for people in need of physical rehabilitation or other health services on a limited yet regular basis. Frequently, providing meals and limited social activity as well, this approach to day care has a strong health care orientation. Multipurpose Model: Programs which provide social interaction and some social and medical services to elderly people in a fixed location for a limited number of hours.	Seen as a needed service for frail and vulnerable elderly who are not being served by the long term care system. Viewed as a way to improve the quality of life of its users.	Moderate amounts of research available which profile existing programs and estimate the potential need for and uses of new programs. Some cost effectiveness data available.

Service or Provider Category	Role in the Continuum	Extent Studied or Research Available
Senior Centers and Recreation Services Programs which increase the elderly's vigor and social interactions by providing formal social activities and a central meeting place. In addition, senior centers act as clearing houses for elderly people in need of information or services.	Seen as a way to improve the quality of life of its users through the promotion of social activity.	Some literature available. Predominantly advocacy pieces with some analyses of successful operational characteristics.
Transportation Services Programs designed to increase an elderly person's mobility by improving his or her financial and/or physical access to transportation. These programs range from the provision of subsidies or public transit systems to the operation of special mini buses for the exclusive use of senior citizens.	Viewed as critical to insure adequate access to community services.	Some research available. Predominantly advocacy in orientation.
Telephone Reassurance A program designed to decrease social isolation by providing regular telephone contact to elderly people living alone.	Seen as a way to improve the quality of life of its users by increasing social interaction and making the users feel secure that help is available in times of emergency.	Little research available. Usually mentioned as part of the long term care continuum in the advocacy literature.
Friendly Visiting A service designed to decrease the social isolation of the elderly through regular in-home visits by professionals or volunteers.	Seen as a way to improve the quality of life of its users by increasing social interaction and making the users feel secure that help is available in times of emergency.	Little research available. Usually mentioned as part of the long term care continuum in the advocacy literature.
Legal Assistance Free or partially subsidized assistance with legal matters, such as wills and tenant rights.	Important to a limited number of people. Normally cited as a way to guard against housing problems such as displacement.	Little research undertaken. Usually mentioned as part of the long term care continuum in the advocacy literature.
Case Management and Chanelling An administrative service which acts as a link between the client and the providers of long term care. Often case management and channelling programs provide client assessment, service plan development and follow-up monitoring.	Viewed as a critical service for all long term care users. Help to assure the appropriate, timely, and cost effective delivery of long term care services.	Considerable research available. Some is advocacy literature, but many studies have been undertaken to estimate the cost effectiveness and analyze organizational forms of various case management models. The Department of Health and Human Services recently let a substantial number of grants for channelling demonstration and planning programs.

- The extent to which he or she can provide for his or her own personal care, such as eating, bathing, dressing, using the toilet or moving about.

- The extent to which he or she can independently run a household and carry out such tasks as shopping, cooking, cleaning or traveling in the community.

While scores along these dimensions are often combined to define an overall level of functional status, the scales need to be disaggregated to identify specific service requirments. These requirements are defined, both by the type of help needed and the degree to which the individual can help himself. The Western Interstate Commission for Higher Education (WICHE) in another report in this series, reviews the range of assessment tools available to states and past experience in applying them.[67]

When the degree of functional impairment among the aged population is estimated using these tools, it appears that a large proportion is either unimpaired or slighly impaired (approximately 40% in the Cleveland-Durham sample) and able to function independently to a substantial degree. Only a small proportion are extremely or greatly impaired and in need of considerable assistance (approximately 17% from the same sample). The remainder (approximately 43%) are mildly, moderately or generally impaired, requiring some assistance.[46]

As these proportions are reviewed for their implications for the public funding of services, two things should be kept in mind. First, some services can be provided in alternative settings. An intermediate care facility, for example, packages housing, board, personal care services, and some medical services in a single setting;

in doing so, it reduces the need for transportation. But these services may also in some cases be provided in an individual's home through a combination of purchased services and contributed effort by family and friends. Much of the research in the long term care field tries to assess how the setting influences the cost and quality of care and outcomes for clients.

The second point to note is that other factors influence the need for purchased services besides the measured level of individual impairment. For example, in a study of the elderly population in Cleveland and Durham, of those who were extremely impaired and who would therefore be likely candidates for nursing care facilities, it was estimated that only 37% were institutionalized.*[46]

An inadequate supply of nursing home beds and non-institutional services and the lack of public funds for some of these services has been cited as a reason why severely disabled people are not always receiving nursing home care or community based purchased services.[101] Yet two other factors also stand out as influencing the use of these services:

- The presence or absence of family and friends who can provide assistance. These may include a spouse or children -- especially non-working daughters -- who live nearby. The aggregate market value of these in-kind services has not been estimated, but there is general agreement that it is extremely large.[18,81,127]

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* This figure is the highest estimate found in the literature of the percent of extremely impaired who are institutionalized.

- Availability of financial resources, either personal or family. The relationship between financial resources and service need is complex. To some extent, those who have funds and need assistance can purchase it. In 1975, for example, it was estimated that private expenditures exceeded public expenditures and that even in the case of institutional care, private expenditures were approximately equal to those of government.[3] In addition, there appears to be a correlation between wealth and lower levels of impairment.[47] There is no research which has determined how these are causally linked, however.

What are the General Analytic Questions Confronting State Officials in the Long Term Care Area?

As state policy-makers confront the long term care system and attempt to establish a state long term care policy, they need to understand the extent to which the state can control each of the programs providing services in order to better respond to and finance long term care needs. Among the analytic questions they must address are:

- What are the programmatic relationships among these activities:

  -- To what extent do programs serve the same or similar populations-at-risk?

  -- To what extent can the priorities and policies of categorical programs be made to complement one another?

  -- What are the trade-offs among programs; if changes are made in one program, how will they affect utilization of other programs? For example, if the number of institutional beds financed by Medicaid is reduced, can non-institutional programs (Title XX and Older American Act programs) produce the necessary services?

- What are the fiscal relationships among these programs:

  -- To what extent will an expansion in public financing simply replace private resources devoted to long term care?

  -- What is the interdependence of these programs? For example, if intermediate care facility services are reduced, how will this influence demand for hospitals, skilled nursing facilities and community-based services?

  -- How will the level of federal funding support change if services are shifted from one program to another?

Much of the analysis that follows in Chapters Two is an attempt to respond to these questions in the context of posssible state policy initiatives.

CHAPTER TWO

CAN THE FINANCIAL BURDEN OF LONG TERM CARE BE CONTROLLED?

One of the critical needs in state health policy is, to the extent possible, to control the financial burden imposed by long term care programs. How this goal is defined can vary considerably from state to state.

- In some cases, states may try to moderate the growth of costs in these programs and develop controls on costs so that future growth can occur at a selected rate.

- Other states may attempt to develop a more appropriate mix of services that provides a level of support comparable to current efforts, but at lower cost.

- Still other states may be willing to reduce the availability of some services if the impact on the client population isn't too severe.

- Finally, states may try to reduce their fiscal exposure by shifting the provision of care or the financial responsibility for it to other units of government or to private resources.

A variety of approaches have been proposed to achieve these goals. Some have involved limiting reimbursement levels.* Others have focussed on changing the mix of services paid for by public programs.

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* The literature on use of reimbursement controls for nursing homes is reviewed in another NCHSR sponsored synthesis entitled A Synthesis of Research on Nursing Home Reimbursement.[113]

This report concentrates on the issues involved in changing the mix of services. These have most often concentrated on reducing institutionalization in nursing homes or other expensive facilities, such as hospitals. Some of these approaches are narrowly focussed on the population currently served by these programs; others are also directed at those who may use these expensive services in the future.

This chapter reviews the potential impact of five broad options that are being discussed in a wide range of states. These are:

- Shifting Clients From Institutional Settings to Community-Based Settings
- Diverting Clients at the Time of Institutionalization
- Increasing Preventive Efforts to Reduce the Long Run Need for Institutionalization
- Increasing the Share of Expenses Assumed by Families
- Reducing Intermediate Care Funded by the State

For each of these strategies, the text outlines the way in which the policy could be implemented, identifies the critical questions that need to be answered to assess the impact of the strategy, and discusses the extent to which the available research can be used to provide answers to the questions.

OPTION 1: SHIFTING CLIENTS FROM INSTITUTIONAL SETTINGS TO COMMUNITY SETTINGS

Since institutional care has been identified as an expensive service by states, an alternative is to reduce the institutionalized population by shifting individuals from nursing homes to community settings. Yet the successful implementation of such an effort would depend on the validity of three key assumptions:

- That there are a substantial number of individuals in nursing homes who do not need the full range of services provided by these facilities.

- That the services this group needs could be provided in a community setting.

- That the costs of community-based care would be lower for the state than the costs of institutional care.

Research findings which help to evaluate these assumptions are examined below.

Are There Elderly People in Institutions Who Need Not be There?

According to the health services research reviewed, a significant proportion of people in institutions have levels of functional impairment that are low enough so that they do not need to be in a nursing facility. Exhibit 2 summarizes seventeen studies that estimate the extent of inappropriate utilization of nursing homes. These estimates vary dramatically between 6 and 76 percent. There are several factors which contribute to this variation:

EXHIBIT 2

SUMMARY OF STUDIES OF INAPPROPRIATE UTILIZATION OF NURSING HOMES

(Listed in Chronological Order With Most Recent First)

Study	Percent of Patients Inappropriately Placed[a/]
Eastern Shore, Maryland 1978 (Delmarva Foundation for Medical Care)	25
National 1977 (Congressional Budget Office)	10-20 SNF 20-40 ICF
New Jersey 1976 (Malafronte et al.)	35 ICF[b/]
Illinois 1975 (Booz Allen and Hamilton)	24 ICF
New York City, 1975 (Gentry and Curlin)	65-76 ICF
Minnesota, 1974 (Greenberg)	18 SNF
Rochester, New York, 1974 (Monroe County Health Council)	10 SNF 35 ICF
National, 1974 (Office of Long Term Care, HEW)	7-13
Massachusetts, 1974 (Beattie & Jordan)	26 SNF
National, 1973-74 (National Center for Health Statistics)	18-22
Minnesota, 1973-74 (Miller et al.)	8 SNF
Rochester, New York, 1973 (Zimmer)	13 SNF 17 ICF
Gainsborough County, Florida 1970 (Bell)	20-30

Study	Percent of Patients Inappropriately Placed[a/]
Durham, North Carolina (Burton et al.)	6
Rochester, New York, 1969-70 (Monroe County Health Council)	48 SNF 74 ICF
Massachusetts, 1969 (Massachusetts Department of Public Health)	40-63
Western New York State, 1967-69 (Davis and Gibbin)	27
Rochester, New York, 1964 (Berg et al.)	48 SNF 21 ICF

a/ Percentages refer to generic category of "nursing home" unless otherwise specifically indicated. SNF refers to Skilled Nursing Facility, ICF to Intermediate Care Facility.

b/ Refers only to the lowest level of ICF care.

Source: Baltay, Maureen,
Long Term Care for the Elderly and Disabled, Congressional Budget Office, February 1977.

Updated with:

Booz, Allen & Hamilton,
Summary of the Major Findings of the Long Term Care Study,
Illinois Department on Aging, Springfield, Illinois, July 1975.

Delmarva Foundation for Medical Care,
"Patients in Nursing Homes with Less than Comprehensive Nursing Need Compared to Hospital Patients Waiting for Nursing Home Beds," unpublished memo.

Malafronte, Donald; Moses, Howard H.; Bronson, Rhona M.; Kunreuther, Carol A.; Breyer, Peter R.,
"Appropriateness of Long-Term Care Placement: A Study of Long-Term Care Patients in the New Jersey Medicaid Program," in The Medicaid Experience, Allen D. Spiegel (editor), Aspen Systems Corporation, Germantown, Maryland, 1979.

- The studies determine need in different ways and criteria are not consistent. In their review of fourteen studies of the appropriateness of placement in nursing homes, the Congressional Budget Office cited the following inconsistencies in method that contributed to the wide range of the estimates:

  -- "variation inherent in subjective judgments of what level of disability requires institutionalization;

  -- the absence of generally agreed upon criteria for institutionalization at particular levels;

  -- use of strict medical necessity versus feasibility of deinstitutionalization as criteria; and

  -- differences in the sophistication of the patient assessment and placement mechanism in each location or in succeeding years."[3]

- The studies were undertaken by different teams of reviewers whose judgments varied. Malafronte et al., made this point when confronted with local variations in recommendations for alternative care settings. The authors concluded that these variations "appear closely related to office caseloads and the subjective personal judgments of individual medical evaluation teams."[79]

- The services provided by SNFs and ICFs vary according to statewide definitions of these terms. The range of services delivered by these facilities influences the extent to which people are appropriately or inappropriately placed in them.

- Some misplacements may be administrative and do not reflect mismatches of clients and services. In states with many ICF levels, for example, clients may not be at precisely the right level (perhaps because their condition has changed) but may nonetheless be receiving an appropriate service mix.

- Community characteristics such as nursing home and hospital bed supply, the availability of community and home-based services, and the existence of utilization review and pre-admission screening activities may influence the level of inappropriate placements in a community.

- Many of the earlier studies were done before effective preadmission screening and utilization review activity were in place. While effective reviews are still non-existent in many localities, improved controls are in operation in some areas. As a result, the number of inappropriate placements may have declined over time.

Clearly the level of inappropriate placement in a particular community cannot be determined by examining national data or studies done in other communities, even if the study design did not influence the estimates. Environmental factors effecting misplacements are highly localized.

Nonetheless, the consistency of these studies in identifying misplacement strongly suggests that misplacements are likely to exist in many communities. After examining the clustering of results from fourteen studies, the Congressional Budget Office assumed "conservatively that 10 to 20 percent of SNF patients and 20 to 40 percent of ICF residents are receiving unnecessarily high levels of care."[3] Other studies confirm this conclusion.[13,31,79] unpublished memo; Malafronte et al., 1976; Booz, Allen and Hamilton, 1975) One study concluded that an even higher percent of ICF residents were inappropriately placed. The authors based their conclusions on very stringent criteria, however.[57]

Misplacement, of course, is not in itself the issue. The issue is whether clients are receiving appropriate services and whether they could receive the services they need at lower cost in a community-based setting. The pool of clients placed at inappropriately high levels of care would, however, be the initial group for which the feasibility of alternative services could be considered.

In discussing misplacements, it should be noted that they may also occur in hospitals. PSROs, hospital organizations, and state auditors from New York, Connecticut, Washington D.C., Massachusetts, California, and Chicago report that elderly people in need of ICF or SNF level care are sometimes being cared for in hospitals because nursing home beds are not available.

While many elderly people are receiving a level of care that is too high, there are also some people who are receiving care at levels that are inappropriately low. In particular, in markets where excess demand for nursing home care exists, Medicaid patients may not be receiving the level of care that they need.[11]

There are several factors which may contribute to this. Reimbursement systems which do not consider the varying expenses related to different service needs within a level of care may discourage nursing homes from caring for severely disabled patients. The access problems created by these reimbursement systems may be exacerbated by planning and investment controls. Certificate of need programs, for example, which determine bed supply on the basis of need assume that all placements are appropriate. Those bed planning procedures would perpetuate a pattern of underservice in the community.[11] In closing it should be noted, however, that the magnitude of inappropriate placements that are too low are considerably below that of inappropriate placements that are too high.[3]

Where Should Efforts to Shift Clients be Focussed?

There are two ways to interpret data which indicate that people are being cared for at unnecessarily high levels of care. These interpretations have different implications for the design of a strategy to shift clients to more appropriate care setttings.

- A limited number of researchers believe that most of the people who could be moved to community-based care settings are currently residing in intermediate care facilities. The Congressional Budget Office, for example, concluded that while the inappropriately placed residents from intermediate care facilities could be cared for in the community, most of the residents of skilled nursing facilities who are receiving care that is too high "still need some form of institutional care."[3]

- Other researchers believe that there are people at every level of care who could be adequately cared for in the community. Thus, deinstitutionalization efforts could take place in hospitals, SNFs, and ICFs.[29,31,57]

The deinstitutionalization component of the New York Long Term Home Health Care Program, usually referred to as the Nursing Home Without Walls Program, is currently operating under this second model. Efforts are being made to move people into community-based settings from SNFs and hospitals as well as ICFs. While program officials have located people who are appropriate candidates for community-based care from all three of

these locations, they have had very limited success in actually transferring these people to community settings. To date, fewer than five people have been transferred to community settings. One program official cited three principal factors which have inhibited widespread movement of people out of institutions:

- Residents of hospitals and nursing homes often lose their homes after extended stays in an institution. The New York Department of Social Services will hold a house or apartment for an institutionalized person for only one month. Yet after the department stops subsidizing rent or mortgage payments, an elderly person frequently does not have sufficient income to continue these payments while paying for institutional care.

- After extended stays in an institutional environment, residents frequently deteriorate to such an extent that community placement is no longer feasible.

- Families are less involved with their relatives after extended institutional stays.

The experience of the New York Nursing Home Without Walls program does indicate that candidates for community-based care, as judged by physical condition and level of functioning, can be found across the spectrum of institutional settings. Yet the efforts of the program suggests that other factors, most notably housing, must be considered in order to implement successful deinstitutionalization efforts.

Before a final judgment can be made on the relative merits of a strategy focussing on moving clients from ICF level care into the community or attempting such efforts across the spectrum of institutional care, states must consider three factors.

First, states must evaluate where most of the clients who could be appropriately cared for in the community are now residing. There is agreement in the research literature that community placement for some residents of ICFs is reasonable in terms of service needs. There is less certainty, however, as to the appropriateness of community care for residents of SNFs and hospitals. As a result, one strategy for states to pursue might be to initially concentrate their efforts on ICF clients while conducting limited tests of the feasibility of community placement for residents of other institutional settings.

States should consider which deinstitutionalization efforts are likely to save them the most money. One study done in a nine county area of New York concluded that 93.2% of all hospital patient days attributed to nursing home back-up were paid for by Medicare, and thus did not impose a financial burden on the state.[38] For states concerned strictly with reducing their costs, this situation would suggest a strategy which concentrates on ICF residents rather than hospital patients.

If improving the likelihood of placement is an important program design criterion, then (based on the experience of the New York State Nursing Home Without Walls program) because extended institutional stays increase the likelihood of a client losing a home, deteriorating in health status, and receiving less care from his or her family, states might concentrate deinstititonalization efforts on hospital patients or on those who have only recently been placed in ICFs or SNFs.

These factors suggest different policy initiatives. Any approach needs to be evaluated in the context of an individual state's situation and should probably be coupled with a state survey of the

number of clients who are potentially candidates for community-based services. The average levels of misplacement cited above may, however, serve as a basis for estimating the potential scope of such a program.

What are the Characteristics of People in Institutions Who Could be Cared for in the Community?

Identification of those in institutions who could be cared for in the community have been made on the basis of functional abilities. Those conducting these surveys consider people with low levels of physical impairment likely candidates for community placement.

Yet the institutionalized population with low levels of physical impairment has several other unique characteristics. The research shows that people in institutions who have low levels of physical impairment tend to lack families and other sources of informal care and financial assistance. One study found that almost two thirds of the unimpaired or mildly impaired living in SNFs did not have living spouses or children.[81] Another study found that 53% of the residents of nursing homes who needed no assistance with activities of daily living except for some help with daily personal hygiene had no regular visitors.[6] In other studies as well, the existence of informal supports has been shown to be a critical determinant of why people at the same levels of function and income live in different settings.[20,70] This is particularly true at low levels of impairment. Thus, the population most likely to be targeted by a deinstitutionalization strategy would be the mildly or moderately impaired with regard to activities of daily living who are without families and other sources of informal support.

What Services Would be Needed to Maintain this Population in the Community?

In order to maintain themselves in the community, the deinstitutionalized elderly would need a range of community-based services. Most notably they would need housing. Many elderly people lose their homes immediately before or after institutional placement and as a result, would have no homes to return to if they were discharged. An Illinois study concluded that 69% of the nursing home population who could be cared for in the community would need housing.[13]

For patients who have entered hospitals for acute care and need ongoing care after discharge, the need to find replacement housing may be less severe. Evaluators of the New York Nursing Home Without Walls Program found that 6% of the hospitalized people eligible for home health care were unable to accept the option because they did not have family or a home to return to.[90]

As well as needing a place to live, a majority of the deinstitutionalized need other assistance. A New Jersey study, for example, concluded that of the 437 institutionalized people in the sample who did not need nursing home care, only 14 could live fully independently in the community. These results are particularly striking in light of the fact that this study only examined recipients needing the lowest level of ICF care. The finding that ICF level 2 clients were in need of support services to live in community settings, strongly suggests that higher level ICF residents and SNF and hospital patients also need assistance.[79]

It is impossible to state the exact mix or magnitude of social services which would be demanded by a community-based population. Elderly people have different needs and even when needs are similar, the appropriateness of specific services to meet these needs differs according to the personality and situation of each person. However, some assumptions about the types of services which would be demanded can be made on the basis of the profile of the potentially deinstitutionalized population.

As was previously mentioned, the candidates for deinstitutionalization would likely have a relatively high degree of functional ability, but lack family. As a result, medical services such as home health and day care would probably not be needed or would be needed intermitantly or for short time periods. Yet other services are likely to be required to replace the informal care often provided by family members. These services include both personal care (assistance with grooming, dressing, bathing, etc.) and housekeeping or chores (cleaning, cooking, shopping, etc.). Results from the Illinois study support this.[13] Whereas only 31% of people with a potential for deinstitutionalization would need medical assistance, 64% would need housekeeping assistance and 69% would need supervision of some type.

Congregate housing or domiciliary care, which offer both housing and medium levels of personal care and housekeeping services, are possible vehicles for meeting these two service needs. The authors of the New Jersey study concluded for the people for whom deinstitutionalization was appropriate, congregate housing was the preferred placement for deinstitutionalization, and advocated it for 71% of the sample.[79]

In congregate housing facilities, each resident usually lives in a separate apartment and has the option of using communal meal facilities and other medical, social, and recreational services. In domiciliary

care facilities, individuals normally have their own or shared rooms, but eat as a group. Other services are often available. Under both of these models, some economies of scale are probably realized as services are provided to many individuals at a single location.

Does Deinstitutionalization Have an Impact on the Health Status of the Elderly?

Some controversy exists over the impact a change in environment may have on the health status of elderly people. Yet, a majority of the research indicates that relocation does not lead to increased risk of death for elderly people. The research does suggest, however, the patient transfer may lead to stress and some "transfer trauma." It must be noted, however, that most of this literature examines the effects of moving elderly people from one institution to another. It is conceivable that deinstitutionalization has a different effect on the health status of the elderly than relocation. Consequently, the results of the studies examined may not be completely transferable.

One review of 23 studies reports that 75% of all relocation studies have found no increased risk of death for elderly people who undergo nursing home transfers.[14] When the sample of studies evaluated was restricted to only those with an experimental-control design, similar mortality rates for relocated and nonrelocated groups were reported for 85.7% of all studies.

A review of 40 studies that examined the psychological as well as physical impact of transfer on the elderly reported some cases in which the transfer process involved some danger for elderly people.[27]

But the authors add that the research is not reliable or consistent enough to determine the full impact of relocations on the elderly. They claim that "the nature and extent of the transfer trauma

that does exist and is documented in the literature, occurs in a minority of the transfers that do take place."

There are several different theories which may explain why transfer trauma seems to exist in a minority of cases. There is some evidence that personality type may influence the degree to which a person suffers from a move.[27] Other studies indicate that the way the move is executed may influence patient outcomes. When patient participation is allowed, for example, or when counseling and advance visits are provided, stress is reduced.[27,139]

Are there Legal Factors Which may Inhibit Deinstitutionalization Efforts?

Presently, there are no federal or state laws which prohibit deinstitutionalization of the elderly. The Federal District Court of the Southern District of New York, however, recently ruled on a case that may have national implications. In Yaretsky vs. Blum, the court decided that nursing home residents cannot be transferred to a lower level of care without a hearing if the resident opposes the transfer and cannot be transferred within a multi-level facility. If the resident does not wish to be transferred, he or she may request a fair hearing before the New York State Department of Social Services. This case, which is under appeal by New York State, may limit a state's discretion to effect transfers.

Will Deinstitutionalization Efforts Promote Cost Savings?

The level of savings that accrue from deinstitutionalization efforts appear to be highly dependent on the definition of costs that are used. When aggregate costs are considered it is unclear whether deinstititonalization efforts are cost effective. When the costs of these efforts are disaggregated to reflect only those costs borne by the state, however, cost savings appear more likely. Yet some of these

savings may not be realizable. An empty institution may cost a community almost as much as a full one. The following discussion examines these issues in more detail.

If a state undertakes a deinstitutionalization program and assumes complete responsibility for the deinstitutionalized population, it is uncertain that savings will be achieved. As was previously discussed, the research literature suggests that congregate housing is the preferred placement for most deinstitutionalized elderly. To the extent that congregate housing is the primary placement, cost savings are contingent on this setting being less expensive than institutional care. Yet evidence on this point is conflicting. A 1976 study by the Department of Housing and Urban Development found that congregate housing costs are highly dependent on the level of service provided and that at the higher levels, costs are comparable to ICF care.[122]

A 1979 GAO report analyzing data obtained from Cleveland and Durham reported that congregate housing is less expensive than institutional care, but this study has several flaws. The most notable is that estimated costs of caring for the institutionalized population was drawn from both skilled and intermediate level care and that estimated costs of congregate housing came not from Cleveland, but from 1974-1975 national data adjusted for inflation.[40] The results of these studies are presented in Exhibit 3.

Placement in domiciliary care facilities is also suggested for some residents of ICFs and SNFs. Yet available national data suggests that the cost per day of domiciliary care facilities is comparable to that of Medicaid ICF care. (Exhibit 4)

There is not adequate research to examine the cost implications of community settings for the deinstitutionalized elderly. While numerous studies examine the cost effectiveness of community versus

EXHIBIT 3

COMPARISON OF COST PER RESIDENT DAY:

CONGREGATE HOUSING VERSUS INSTITUTIONAL FACILITIES

FACILITY	COST PER RESIDENT DAY
Department of Housing and Urban Development Estimates, 1976:	
Congregate Housing	
Medium Service Level (1974-1975)	$10.45
High Service Level (1974-1975)	15.17
National Nursing Care Cost	
Average for All Facilities (1974)	15.96
Average for ICF Certified Beds (1972)1/	11.95
Average for SNF Certified Beds (1972)	20.47
GAO Cleveland Estimates, 1979:	
Congregate housing (1974-1975 data adjusted to 1977 dollars)	$11.32
Institutional Care (1976-1977)	15.27
Community Care (1976-1977)	13.95

1/ 1974 data not available

Source: General Accounting Office,
"The Potential Need for and Cost of Congregate Housing for Older People," Memorandum to the Chairman and the Ranking Minority Member, Special Committee on Aging, U.S. Senate, October 1979.

U.S. Department of Housing and Urban Development, Office of Policy Development,
Evaluation of the Effectiveness of Congregate Housing for the Elderly, prepared by Urban Systems Research and Engineering, Inc., Cambridge, Massachusetts, September 1976.

EXHIBIT 4

ESTIMATED SPENDING INCURRED FOR NURSING HOME AND PERSONAL CARE FACILITIES, FISCAL YEAR 1976 a/

	Average Patients (Millions)	Cost per Day b/	Spending b/ (Millions)	Federal Programs c/ (Millions)
Skilled Nursing Facilities d/	913		$ 8,705	$ 4,250
Medicare	28	$36.20	370	310
Medicaid, as SNF Patient	395	25.60	3,690	2,750
Medicaid, as ICF Patient	204	19.25	1,435	1,070
Private or Other Funds	286	30.75	3,210	120
Intermediate Care Facilities e/	350		1,915	1,225
Medicaid (as ICF Patient)	300	$14.20	1,555	1,165
Private or Other Funds	50	19.80	360	60
Personal Care Facilities with Nursing f/	185		1,445	70
Assistance Recipients	75	$17.60	480	0
Private or Other Funds	110	24.00	965	70
Personal Care Facilities without Nursing g/	7	$14.10	35	10
Total	1,455	$22.80	$12,100	$ 5,555

a/ Includes all spending for services provided in fiscal year 1976, regardless of when paid.

b/ Includes 1.5 percent allowance for profit or retention by nonprofit facility.

c/ Total program outlays incurred, including final settlement payments, for services provided in fiscal year 1976. Excludes administrative expenses.

d/ Facilities certified as SNFs by medicare or medicaid.

e/ Facilities certified as ICFs by medicaid, but not certified as SNFs.

f/ Facilities included in the MFI as nursing care or personal care homes with nursing, but not certified as SNFs or ICFs.

g/ Facilities included in the MFI as personal care homes without nursing, or domiciliary care homes.

Source: Baltay, 1977a.

institutional settings for elderly people, the studies do not examine the special problems of the deinstitutionalized. Rather they examine the cost effectiveness of community placement for those people who have not yet entered institutions.

In order to estimate the full cost impact of community placement for deinstitutionalized elderly people, governmental contributions to rent and food costs must be considered as these expenses are included in the cost estimates for institutional care and congregate housing placement. One study by GAO which imputes these costs has reported that the cost of caring for clients in community-based settings exceeded that for congregate housing, but is less than institutional placement. The study compares community costs in Cleveland for people who could use congregate housing to a composite cost for institutional placement drawn from Medicaid costs for SNFs and ICFs. (See Exhibit 3)

Another factor which should be considered when evaluating the full cost impact of community placement is the administrative costs associated with assessing the institutionalized population, developing a service package for them, paying for the service package, assuring the quality of services provided and monitoring the effected population in the community. This would have to be done locally because staffing and administrative practices, evaluation designs, and other factors vary from locality to locality. While these costs should be considered when evaluating placement in congregate housing or domiciliary facilities as well, they are expected to be highest for community placement as monitoring and quality assurance efforts would be decentralized.

Although it is unclear whether deinsititionalization efforts are cost effective in the aggregate, there is the possibility that these efforts may save states money if they are able to shift some of the cost of caring for the deinstitutionalized to families or to the federal government.

Families are an unlikely source of additional support for the deinstitutionalized population, as their level of support is already quite high. (See pages 66-69) In addition, as was previously noted, the most likely candidates for community placement based on functional status are institutionalized people who are mildly or moderately disabled but normally do not have sources of social support.

Nor is the individual a likely source for funds. The most common source of income for the elderly being supported in institutions is Supplemental Security Income (SSI). Yet SSI would not be sufficient to pay for the necessary community-based services following deinstitutionalization. In any case, the portion that it could pay would not be new income to the state as it is already being used to offset state institutional costs.[88]

Thus, the most likely source of additional funds for non-institutional care is the federal government. If the state is to reduce its own costs through a deinstitutionalization program, it may be necessary to redeploy the current federal/state benefit programs in a way that expands provision of community-based care while minimizing the state share of these expenditures. While the redeployment devices available to state governments are limited, there are some areas for states to pursue.*

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* This redeployment of fund sources could accompany a shift of an individual to a lower level of institutional care, as well as full deinstitutionalization. For example, an elderly person currently residing in a medical facility, and whose care is financed by Medicaid, could be transferred to a non-medical congregate setting. The SSI payments made to the individual could be used to pay for the major portion of care in this non-medical setting, with state supplementation to the full cost of care. Depending on the relative costs to the state of various levels of institutional care and the size of federal SSI payments, this might result in either higher or lower total costs for the state.

The Medicare and Medicaid Amendments of 1980, for example, expand the states' capacity to guarantee home care services to elderly people at minimal cost. Under the new amendments, all homebound (although not necessarily bedridden) elderly who are eligible for Medicare Part A or for whom the state may buy Part B coverage may receive unlimited numbers of the following services in their homes: nursing care, physical therapy, occupational therapy, medical-social services, assistance from home health aides, and medical supplies and appliances. As a result, at no or minimum cost the states might provide home care to deinstititnalized elderly people in need living in their own dwellings, a relative's home, congregate housing facilities, or domiciliary care homes.

Although support is limited, there are federal funds for other non-institutional services as well. Income support is provided through SSI, state supplemental payments to SSI, and Social Security. Reimbursement for social service costs may be obtained from the Title III and Title XX programs (although many states are at their Title XX ceilings). Federal support for congregate housing or group housing is available, but is extremely limited. The Section 202/8 and Section 236 housing subsidy programs remain small in scale.

The preceeding discussion suggests that deinstitutionalization efforts might prove cost effective to the states if they can redeploy some of the costs of this program to the federal government. Yet before this suggestion can be validated, a full analysis of the cost impact of this option needs to examine the second order effects of moving people from institutional settings.

Deinstitutionalization efforts may actually initially increase total costs to the states because they may be forced to bear the large fixed costs of emptied institutions while subsidizing community care. The National Nursing Home Survey suggests that approximately 15% of the costs of institutional care are fixed. If this figure were accepted for planning purposes, in order for states to achieve a net saving, alternatives must cost less than 85% of institutional care.

It should be noted that the National Nursing Home Survey's definition of fixed costs is extremely narrow. While there is little research available that directly examines the relative size of fixed and variable costs in nursing homes, a number of studies have been done on the impact of changes in volume on the average costs of care.[10] Our reanalysis of the findings of several of these studies suggests that the percent of nursing home costs which are fixed may actually be higher than 15%, and that the relative cost of alternatives would, therefore, have to be less than 85%.

Cost savings to the community by reducing unnecessary acute hospital days need to be analyzed in the same way. The literature on fixed and variable costs in hospitals is more extensive than that on nursing homes, and it has been found that in the short run, fixed costs represent 50-60% of the cost of a day of care.[75]

For both nursing homes and hospitals, these short term marginal costs may lead to long run savings in fixed costs. By emptying facilities, deinstitutionalization efforts might lead to closing facilities or slowed growth of new facilities. Clearly cost implications of the second order effects of moving people out of institutions must be evaluated on a local basis as fixed costs, certificate of need controls and other factors vary.

Another potential second order effect that could reduce net savings might be the movement of clients into the vacated beds from other settings. Research suggests that the demand for nursing home care exceeds the supply. The Congressional Budget Office estimates that 10% of all nursing home beds could be filled by people in acute care hospitals and the community.[3] Because the prevalence of people in hospitals waiting to be placed in nursing homes varies considerably according to geographic region, however, the potential saving which may be accrued from opening up nursing home beds to those in acute care settings, needs to be evaluated on a local basis. Furthermore, there is a possibility that emptied beds would be filled by those from the community rather than acute care settings. If these individuals were receiving services prior to entering the facility, the costs of this client would represent an offset to the savings from the client transferred out. If the new client had been receiving services, the aggregate cost of which were higher than the cost of nursing home care (as might be the case if the new client were significantly impaired), then further cost savings might be realized.[3,101]

In conclusion, although deinstitutionalization may not result in lower aggregate costs, a deinstitutionalization strategy may be a cost-effective strategy for the state. Cost savings would be dependent on keeping the vacated beds unfilled or filling them only with clients from more costly care settings (controls that the state experience noted above suggests are very difficult to maintain), or on shifting financial responsibility to the federal government or families. Because the cost saving potential of this strategy for states is dependent upon states sharing some of the costs of caring for the deinstitutionalized population with the federal government, the feasibility of this strategy is dependent upon federal funding for building and maintaining an adequate supply of housing resources and/or for delivering a range of supportive services to the deinstitutionalized population. Finally, it should be noted that a full analysis of this option requires consideration of the potential second order effects of either leaving the vacated nursing home beds unfilled or replacing the shifted clients with individuals currently in hospitals or in the community.

OPTION 2: DIVERTING CLIENTS AT THE TIME OF INSTITUTIONALIZATION

An alternative to a strategy which attempts to move individuals from nursing facilities after they have entered them is one which attempts to divert clients from nursing homes at the time that they try to enter them. Such a program would deny nursing home care to Medicaid eligibles who can be appropriately cared for in the community and would ensure the availability of community services to them.

This approach is based on two assumptions. First, it assumes that intervention at the time of proposed institutionalization is early enough to effectively divert significant numbers of clients. Second, it assumes that the strategy reaches a large enough proportion of Medicaid eligibles to achieve a significant cost saving. This section reviews the health services research related to these assumptions.

Are There Elderly People Who Apply for Nursing Home Care Who Could be Cared for in the Community?

The discussion of inappropriate placements on pages 19-24 suggests that there might be significant numbers of people in institutions who could be cared for in community-based settings. This suggests that many of those people who enter nursing homes could be maintained in the community if adequate support services are made available.

What Services are Needed to Maintain this Population in the Community?

To maintain this group in the community, the housing and supportive service needs of these people must be provided for. It is likely that most people in the target group will currently have housing in the community, since the major trigger of the decision to seek

institutional care is not loss of housing but the the death of a spouse or caretaker or a medical or financial crisis.[18,20,39] If these people and their families are reached before institutionalization occurs and consequently, current housing is retained, they might be served in the community without housing assistance from the state.

This is not true in every area, of course. In some geographic areas, the loss of a home is a widespread and major contributor to institutionalization. For example, according to an informal survey of social service agency personnel and employees of the Office on Aging, condominium conversions force many old people to consider institutionalization in the District of Columbia.[74] Other factors such as redevelopment efforts, may destroy housing units and disrupt neighborhoods and their informal support systems; they may also contribute to the displacement of elderly in urban areas.

The feasibility of this strategy may, therefore, vary substantially by locality. As a result, an estimate of the housing needs generated by this program must be undertaken at the community level.

The supportive services needed by this population would be similar to those identified for clients in nursing homes who could be cared for in community-based settings -- some medical services, but primarily homemaker, chores, personal care, and some supervision. This is supported by the experience of New York and Virginia.[39,90]

How Well do Programs that Divert People at the Time of Institutionalization Operate?

A review of three gatekeeping programs is provided in GAO's Entering a Nursing Home -- Costly Implications for Medicaid and the

Elderly.[39] The authors conclude that all the programs prevent or postpone entrance to institutions. The three programs discussed are those in Virginia, Monroe County, New York; and New York State.

The State of Virginia has established a preadmission screening program which reviews all community residents who are Medicaid eligible or who will become Medicaid eligible within 90 days of institutionalization. The state denies payment for nursing home care when community care is acceptable and available for these people. According to program statistics, between May 15, 1977 and February 28, 1979, 3,592 applicants to nursing homes were screened. Twenty-one percent these applicants were maintained in the community.[39] (Department of Health and Medicaid Mangement, Richmond Virginia)*

Under the Monroe County ACCESS Project, all Medicaid long term care clients are required to use this service. In addition, clients who will pay for their own care are encouraged to use the service on a voluntary basis. ACCESS statistics indicate that 69% of assessed Medicaid clients and 58% of private pay clients remain in the community. Because in many cases, ACCESS screens clients who have not yet applied to nursing homes these statistics should be viewed critically. It is possible that many of the clients referred to community care would have remained in the community even without the screening program.[36] (Monroe County Department of Social Services, Rochester, New York)

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* The state is currently reviewing a proposal to expand this program to cover hospital residents who apply for nursing home care and anyone applying for nursing home care who will become eligible for Medicaid within 13 months.

The New York Long Term Home Health Care Program (Nursing Home Without Walls) also has a preadmission assessment component. It covers all Medicaid eligibles considering institutionalization who have been medically assessed to need SNF or ICF care but who would prefer to remain in the community. Those who may be appropriately cared for by a community-based service package that would cost the state less than 75% of the cost of a nursing facility are given a community placement. It is not clear whether this program acts exclusively as a substitute for institutionalization. In some cases it may be reaching people who would never have been institutionalized (even though judged to need such care).[90] (Office of Health Systems Management, New York State Department of Health)

There are several other states which also operate gatekeeping programs. Montana, for example, has developed a preadmission screening program by contracting with the Montana Foundation for Medical Care to provide medical reviews and hiring a limited number of social workers to perform psycho-social reviews to determine the feasibility of community placement for those people who qualify for institutional level care from a medical standpoint. Unlike other programs, the Montana program does not review all Medicaid eligibles. Economic constraints have forced administrators of the program to target resources at those people in urban areas who are at the greatest likelihood of qualifying for community placement.

A review of existing or planned programs in Oregon, New Jersey, South Carolina, and Georgia as well as Montana, Virginia, Monroe County, and New York State indicates that states have developed gatekeeping strategies for various reasons:

- In all of the states reviewed there is considerable concern over the rapid increase in nursing home costs as a percent of Medicaid expenditures. Gatekeeping programs are seen as one way to limit these cost increases.

- In a limited number of states reviewed, by determining the number and years of services needed to keep people out of institutions, gatekeeping programs are also viewed as a way to assess the state's needs for non-institutional services.

- In several states, gatekeeping programs have grown out of a dissatisfaction with existing programs developed to discourage institutionalization. In these states, program administrators have concluded that a gatekeeping program is the most effective way to target non-institutional services to people who are at highest risk of institutionalization.

Despite their varied objectives, these programs share many characteristics. In fact, all of these programs follow one of two models of gatekeeping programs:

- The first model both stops people from entering institutions when community services are available and less expensive than institutional care and prevents people from using SNF level services when ICF level care is appropriate. Because the principal purpose of this strategy is to save money, only those people who have applied for institutional care and are therefore traditional beneficiaries of the system are served.

- The second model discourages people from entering institutions by advocating community-based care whenever possible. By design it is oriented toward reaching those in the community who need community-based care, whether or not they are contemplating entering a nursing facility. As a result, this strategy may expand the base of people served by the system and subsequently increase costs.

These models improve upon the assessment mechanisms currently operating under Medicaid for several reasons. Physician's certification of need, utilization review, independent professional review, and medical reviews vary from state to state. In most cases, however, they are not effective in keeping unnecessary placements out of nursing homes for two principal reasons[39]:

- The physician's certification of need and medical reviews occur before placement, but they are medical in orientation. In general they do not evaluate other factors, such as income and the availability of informal supports which affect the appropriateness of community-based alternatives to nursing home placement.

- Utilization review and independent professional review occur after placement has occurred at which time discharge to the community is difficult or impossible.

There are problems associated with preadmission screening programs, however:

- In those states where hospital patients are not screened, there is anecdotal evidence of people entering hospitals in order to be assured entrance into nursing homes.

- In many areas, states have an insufficient supply of community-based services to actually carry out the recommendations of the screening committees.

- Some states have reported difficulties administering the program because of conflicts in the judgments of the medical reviewers and the social workers.

- In some areas, hospital discharge planners have opposed the programs.

Will Diverting Clients at the Time of Institutionalization Promote Cost Savings?

The cost saving potential of gatekeeping functions will vary according to the model used. As was mentioned previously, one model's primary purpose is to save money. It does this by serving people who would otherwise be served by institutions in the community whenever community services are available and less expensive. The other model may increase costs as it has an additional purpose of active outreach to people with unmet needs. It therefore tends to increase the service base.

Yet both approaches may encourage prudent purchasing of services by the state. Savings may be accrued by establishing a policy which only diverts clients to community care when the costs to the state are less than those of nursing home care.

New York's Nursing Home Without Walls Program is set up under this model. Community care is provided only if it is appropriate and its total monthly cost to the state is limited to 75% of the cost of nursing home care. Administrators of the program have suggested changing this regulation so that people who have initial monthly expenses that exceed

75% of the cost of nursing home care may still be admitted to the program provided that their projected annual costs do not exceed the 75% cap.[76,90]

According to program statistics, considerable cost savings have been achieved. The average monthly cost for each participant is $785. This is an estimated monthly savings of $566 over long term institutional care and $6,000 over acute care per patient month.[76] Because the majority of patients have been referred from hospitals, significant aggregate savings are likely. These cost figures should be viewed critically, however. Even in the absence of the program, some participants may never have entered a nursing home. Fifty-one percent of the clients of the Nursing Home Without Walls program live with a spouse or other relative and an additional 4% live with friends. According to program reviewers, in the cases where participants live alone, families frequently live nearby and provide support.[90] Because the existence of informal supports (such as living with others) is a major factor in influencing risk of institutionalization, the Nursing Home Without Walls population may not be completely comparable to an institutional population (see page 60).

Clearly the potential for cost savings exists. What is the magnitude of these potential savings? In order to save money, a diversion strategy must reach a significant proportion of those clients who are costing the state money. The State of Virginia has a unique preadmission screening program in this regard. The Health Department screening committee has the ability to deny Medicaid payments to nursing home applicants who are Medicaid eligible or who would become eligible for Medicaid within 90 days of admission if the committee determines that the applicant may be maintained in the community with the assistance of available services. (A state legislative task force is currently considering a suggestion to increase this eligibility criterion to those who would become eligible for Medicaid within 13 months.)

There is evidence that this approach reaches a substantial percentage of Medicaid recipients. According to the GAO's review of studies which examine the transition of nursing home residents from private pay to Medicaid, conversions represent 30-48% of all nursing home residents supported by Medicaid.[39] Yet a large percentage of these conversions occur within a short time after admission. The GAO study estimated that 23% of all conversions occur within 90 days of admission; an additional 18% come within 6 months. By combining the results of several limited studies, a rough approximation of the percent of Medicaid recipients who either enter nursing homes as Medicaid recipients or who later convert to Medicaid status is presented in Exhibit 5. This gives some indication of the percent of Medicaid recipients who could be evaluated for community placement according to various screening criteria.

In conclusion, diverting clients at the time of institutionalization is a promising cost saving strategy. While there are limits to crisis-oriented intervention and some clients may enter institutions who, with more planning and earlier provision of services may have been kept out, the material presented in this section indicates that late intervention may successfully divert significant numbers of nursing home applicants. Its successful implementation appears to depend on several factors:

- Clear understanding of the purpose of the program as cost containment and the establishment of eligibility criteria based on this understanding.

- Effective assessment tools.

- Quality assurance programs that guarantee that Medicaid eligibles are not being denied needed care.

- Needes services being available.

EXHIBIT 5

MEDICAID CONVERSIONS

Time of Eligibility	Percent of all Medicaid-Financed Nursing Home Clients
Medicaid eligible at time of admission	52-70%
Medicaid eligible within 90 days of admission	11- 7%
Medicaid eligible after 90 days but within 6 months of admission	9- 5%
Total Medicaid clients who are eligible at the time of admission or become eligible within 6 months	72-82%

Estimated from data in: General Accounting Office, Entering a Nursing Home -- Costly Implications for Medicaid and the Elderly, 1979.

- Appropriate and nondiscriminatory application of criteria to determine the need for services.

- Legal ability to require future Medicaid beneficiaries to undergo screening at the time of institutionalization.

OPTION 3: INCREASING PREVENTIVE EFFORTS SO AS TO REDUCE THE LONG RUN NEED FOR INSTITUTIONALIZATION

A policy of promoting long term preventive strategies to reduce the need for institutional long term care is an option which many states are pursuing. The rationale behind this strategy is that for chronic care, like acute care, prevention is a less costly option than treatment. In the states, prevention strategies have taken the form of various non-institutional services, such as home care or day care directed at individuals who do not currently need the level of services provided in institutions. The discussion which follows focusses on four of these services that have been frequently claimed to influence the need for other medical services and for which substantial research has been done. These are:

- Home care services are a group of long term care services provided in an elderly person's home. As used here, they include medically oriented home health services, personal care services, and chore/homemaker services. Home health services include care which relates to cleansing wounds and changing bandages, monitoring and evaluating health conditions as they relate to the treatment plan, giving injections, inserting catheters and IVs, supervising physical therapy and occupational therapy, teaching people to provide skilled care to themselves, and other services which require skilled nursing care. Personel care services include assistance with such activities as grooming, bathing and dressing. Chore/homemaker services include home maintenance services such as cooking, cleaning and shopping.

- Adult day care programs provide medical, nursing, rehabilitative, and recreational services to elderly people in a central location for a limited amount of time. Despite differences among individual day care programs, they generally fit one of two models:

  -- The medical model, in which the center specializes in delivering physical rehabilitative services or other medically oriented care, such as teaching people to provide skilled care to themselves, monitoring and evaluating health status as they relate to treatment plans, and injections.

  -- The multipurpose model, in which the center emphasizes recreational activity and social interaction, in addition to medical care.[53,112,134]

- Congregate housing is a community living environment for groups of elderly people. Some medical and supportive services are provided to its clients, either through direct delivery or referrals. Thse services vary substantially from site to site, but may include group dining facilities, help with shopping, transportation, assisting with heavy housekeeping and recreational activities.

- Two models of nutrition programs exist. The first, congregate meal services, provides inexpensive nutritionally sound meals to elderly people in group settings. The second, meals-on-wheels, brings pre-prepared meals to people in their own homes. Both programs are seen to serve two purposes. First, by supplying nutritionally sound meals to people who might be unwilling or unable to prepare them for themselves, they promote health maintenance. Second, they prevent the social isolation of people who might otherwise be without outside contact.

The potential of these services to save the states money is dependent on several factors. First these services must delay or prevent institutionalization. Second, on an individual client basis they must be less costly to the state than institutional care. Finally, the delivery of non-institrutional services must be targeted at people who are at high risk of institutionalization so that the net savings per client are not totally offset by the larger base of clients served. Available research suggests that some services may delay or prevent institutionalization although the cost-effectiveness of these services is unclear. Even when these services are cost effective, however, it is unlikely that they can be targeted at only those people who would need institutional care in the absence of non-institutional alternatives. Further discussion of these findings is provided below.

Are There Services Which Delay or Prevent Institutionalization?

When the needs of elderly people can be clearly articulated and when these needs can be served in limited periods of time, non-institutional services may delay or prevent institutionalization. The quantity and reliability of research to support this finding, however, varies by service. Specific findings are detailed below.

There is some evidence to support the idea that home care services prevent or postpone deterioration in health status so as to alleviate the need for institutionalization. In some cases, levels of physical functioning, contentment and mental status are actually improved through the use of home care services.[17,35,90,109,132]

In addition, home care may provide some of the same services or provide different services which address the same needs as institutions. Visiting nurse associations and other home health agencies have shown that some services that have traditionally been provided by nursing homes may be provided in the home by home health nurses and aides. Some medically oriented services normally associated with nursing home care, such as cleaning wounds, changing bandages, giving injections, inserting catheters and IVs, and physical and occupational therapy may be provided in a home setting. Other services provided by nursing homes which may be provided in the home include bathing, grooming, and cooking.[17,90,105,109]

There is very limited research which examines whether adult day care services prevent or delay institutionalization, either by providing some of the same services as institutions or by leading to improvements in physical and social function and thus decreasing the risk of institutionalization.

Current findings indicate that adult day care programs have a positive impact on health status.[106,132] Unfortunately, the studies do not monitor these findings over time to determine whether day care induced improvement in health status lead to a decreased incidence of institutionalization.

It is also difficult to determine whether day care programs replace institutional care for some populations. Only one study examines the immediate effect of day care on a clients' risk of institutionalization. The study found that use of a skilled nursing facility by users of day care services was lower than that of the control group.[132] The author cautions that the findings may overestimate the substitutability of day care programs for institutions (SNFs and hospitals) because "initial small, not statistically significant

differences between the experimental and control groups might have played a role in influencing findings." The proportion of people in the experimental group who were under 75, had not been recently hospitalized, and lived with others was lower than in the control group. In fact, the author concludes that despite the findings that use of SNFs was lower "for a significant proportion of the experimental group, day care served as an additional benefit under Medicare, rather than one which was substituted for nursing home care."

At the same time, the study may have underestimated the potential of day care programs to substitute for nursing home care because it only examined utilization statistics for skilled nursing facilities. (The study examined only a Medicare eligible population.) It therefore left untested the potential of day care to substitute for ICF care, a significant possibility given the lower impairment levels associated with that level of care.

There is insufficient research to determine whether congregate housing delays or prevents institutional care by either preventing deterioration in health status or providing many of the same services as institutional care.

One study concludes that congregate housing may substitute for institutional care by providing needed supportive services. In another study, congregate housing residents were found to have decreased risks of institutionalization but increased risk of hospitalization.[104] There are two ways in which this latter finding might be interpreted:

- Increased risk of hospitalization for residents of congregate housing may indicate that their health status is below that of the general population. If their health status when they entered congregate housing was lower than that of the general population, this might explain this finding. If their health status when they entered the facility was equal to that of

the general population, this would contradict the hypothesis that congregate housing prevents or postpones deterioration in health status.

- Increased rates of hospitalization for residents of congregate housing may indicate that residents of congregate housing monitor their health status more closely than non-residents and are more likely to seek medical care. This theory would support the hypothesis that congregate housing prevents or postpones deterioration in health status.

While nutrition programs have the potential for delaying or preventing institutionalization, there is insufficient research to determine whether they actually do.

According to information supplied by the Senate Select committee on Nutrition and Human Needs, the provision of regular well balanced meals to elderly people may prevent or postpone institutionalization in the long run by discouraging deterioration in an elderly person's health status. The Committee estimates that 26% of all people over 60 are undernourished. An additional undefined number are overnourished or obese. The medical effects of malnutrition on the elderly are multiple. For example, inadequate iron intake contributes to weaknesses and ill health, insufficient vitamin C intake may lead to fatigue, aching joints and swollen gums, obesity increases the risk of coronary heart disease, hypertension, stroke, diabetes, gall bladder disease, arthritis, pulmonary dysfunction, and sleep disorders, and general nutritional deficiencies may lead to senility and depression.[124]

While nutrition programs attempt to correct these nutritional inadequacies, it is unclear whether the provision of home delivered or congregate meals alone are sufficient to make up for life-long eating habits. In addition, it is unclear whether these programs are adequate antidotes to health problems related to low income and the aging process.

There is even less evidence on which to determine whether nutrition programs provide a substitute for institutions for the vulnerable elderly. Clearly they do not deliver the same services as institutions. While institutions supply a wide range of services, including food, shelter and medical care, nutrition programs have a very narrow focus. Yet one study suggests that for some people, the delivery of home delivered meals may substitute for institutional care. The study reports that 34.8% of a sample of recipients of meals on wheels would be institutionalized without the service. It should be emphasized, however, that this conclusion is based on the responses of program paticipants to the question "What is your alternative to home-delivered meals in the case of program termination?" Enthusiastic participants may have overstated their dependence on the program.[124]

Do These Services Provide Care in a Way That is More Cost Effective Than Institutions?

There are a large number of studies which compare the relative costliness of non-institutional services and institutional care. Despite the existence of these reports, it is difficult to judge with accuracy the relative costliness of home care, day care, congregate housing, and nutrition programs as compared to institutional care. The research literature has a great many methodological weaknesses that limit the certainty with which conclusions can be drawn. These include:

- Inconsistent definitions of cost and benefits that vary from study to study.

- Inappropriate time intervals are used to measure cost and benefits.

- Inadequate precautions to insure that the population using non-institutional services and the population using institutional services are similar.

- Inadequate consideration for the quality of care delivered by different services.

Despite these problems, there are some indications of the relative costliness of two non-institutional services.*

- In some cases home care may be a cost-effective alternative to institutional care. The relative costliness of home care services, however, is influenced by a variety of factors:

  -- Functional status of the clients[59,68,90]

  -- The presence of informal supports[68,71,99]

  -- The type of agency providing the service (costs in one study were found to be the highest for private non-profit agencies).[109]

- There is very limited evidence to suggest that adult day care is not a cost-effective alternative to institutional care. While there is an absence of consistent cost effectiveness studies that are relevant to the states, it should be noted that during a conference on adult day care programs, experts in the field concluded that this service is more expensive than institutional for anyone who uses it more than a few days a week.[78]

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* A more detailed review of studies which examine the cost effectiveness of home care, day care, congregate housing, and nutrition programs is provided in Expanding Long Term Care Efforts: Options and Issues in State Program Design, the companion synthesis to this one.

Can Prevention-Oriented Services be Exclusively Targeted at People Who Would use Institutional Services in the Absence of Non-Institutional Alternatives?

If new preventive programs only expand present programs and maintain current eligibility criteria and outreach efforts, it is unlikely that they will reach groups who are at highest risk of institutionalization. Research on institutionalization indicates that the strongest factors associated with the risk of institutionalization are, in order of importance:[3,6,18,20,39,67,70,81,101,128]

- Lack of informal providers. The absence of a family member or close friend who provides assistance with transportation, housekeeping, and personal care (bathing, grooming, dressing, etc.) has been shown to be the single greatest predictor of institutional placement. While in some cases children, siblings, neighbors and others serve this role, most frequently it is the spouse who is the informal provider of care. When a person's spouse dies or is institutionalized, his or her risk of institutionalization increases markedly.

- Low income. The research shows that people with low incomes are at higher risk of institutionalization than people with high incomes. There are two possible explanations for this phenomenon:

  -- Older people with low incomes may be unable to purchase food, rent, clothing, nursing, medical care and other services associated with living in the community. Given federal and state subsidies for institutional care, nursing home placement may be the most feasible and affordable living option for low income elderly.[39]

  -- Low income elderly have lower health status than high income elderly. Their physical or mental disability may then lead them to need or seek nursing home care.[93]

Lower income might contribute to lower health status by preventing individuals from being properly treated, or poorer health status may cause income to decline.

There is no research that effectively determines which of these explanations is most correct.

- Physical or mental disability. Difficulties with physical or mental function increase the likelihood of institutional placement as they decrease an elderly person's capacity for independent living and increase his or her dependence on informal or formal providers of care, homemaker and chore assistance and personal care. While a certain level of disability is required for entrance into a nursing home, it should be noted that the level of disability, alone, is only one factor leading to institutionalization. Usually, it is not until the effects of disability are exacerbated by lack of informal supports or low income, that institutionalization is necessary.

Unemployment and advancing age are factors that has been associated with higher risks of institutionalization. They may, however, be correlated with low levels of functional status or income, rather than having a separate influence on risk.

Although non-institutional services have been successful at reaching low income populations and in some cases the physically impaired, for the most part they have not been successful at reaching those people at highest risk of institutionalization: those without families or other sources of informal assistance. (They may be reaching families who, without these services, would be unable to maintain their relatives in the community, however.*)

* More detailed information on which population groups are served by individual services is provided in Expanding Long Term Care Efforts: Options and Issues in State Program Design, the companion synthesis to this one.

The use of non-institutional services by people without informal supports has not been addressed by the research. Yet one measure, which may be correlated with the absence of informal supports, has been evaluated. This is the extent to which users of these services live alone. A review of the literature suggests that the following services do not disproportionately reach elderly people living alone:

- Home Care[5,68,71,76,109]
- Day Care[98,106,112,125]

There is some evidence, however, that congregate housing facilities and congregate meal services may be reaching this high risk group.[45,121,122]

If new programs are to be focussed on preventing institutionalization, they must be better targeted to high risk groups, with eligibility based on the proven and systematic indicators of risk that were indicated previously. Yet even these indicators are not precise enough to successfully identify only those at highest risk. While researchers agree that the lack of informal providers, low income, and physical or mental disability increase the risk of institutionalization, they are careful to point out that any one of these factors does not explain institutional placement:

- The absence of an informal provider is judged to be the single greatest predictor of risk of institutionalization. Yet over one half of nursing home residents have a spouse or child.[39] Clearly other characteristics of the client are

important, such as level of disability and income of the elderly person and spouse, employment, and geographic proximity, sex, age, and income of the child.[127,128]

- Low income groups are considered to be at higher risk of institutionalization than wealthier elderly. One third of the elderly population in nursing homes, however, reported yearly incomes of over $15,000.[39]

- There is considerable disagreement over the extent that impairment increases an elderly persons risk of institutionalization.[6,18,39] Exhibit 6 illustrates the variation in estimates for the percent of those in institutions who are unimpaired or are no more than moderately impaired. Among the factors that may be contributing to these varying estimates are:

  -- Geographic locality, with variations in preplacement screening or availability of non-institutional alternatives influencing placement of the moderately and slightly impaired

  -- Instruments used to measure impairment.

  -- Differences in study designs and sampling.

  -- Day-to-day change in client condition that can result in swings in assessment of functional status.

In conclusion, while this strategy may benefit elderly people, it cannot be guaranteed to promote cost savings for two reasons:

- First, while it is plausible that providing some of these services before clients consider institutionalization will reduce institutionalization rates in the future, this has not yet been conclusively demonstrated.

EXHIBIT 6

PERCENT OF POPULATION AT VARIOUS LEVELS OF IMPAIRMENT IN INSTITUTIONS AND IN THE COMMUNITY: ESTIMATES FROM VARIOUS STUDIES

STUDY	LEVEL OF IMPAIRMENT		
	Unimpaired - Mildly	Moderately	Generally - Totally
Institutional Residents[1/]			
GAO (1979a)[2/]	36.3	32.5	31.4
Brody (1979)[3/]	20.7	16.7	62.6
Barney (1973)[4/]	41.3	33.3	25.4
Non-Institutional Population			
Brody (1979)	60.0	17.0	23.0
GAO (1977a)[5/]	66.0	12.7	34.0

1/ Institutional residents have been estimated at between 4-5% of the total over 65 population.

2/ Data interpreted from the Survey of Institutionalized Persons. Classifications of impairment levels varied slightly from those in the table. The estimate for those in the "unimpaired - mildly" impaired category came from data classified as "no dependence" to "slight and irregular dependence." The "moderately" impaired classification combined statistics for "moderate but irregular dependence" with "moderate and more regular dependence." The "generally - totally" impaired classification incorporated data originally labled "consistent dependence in most self-care activities to "extreme dependence in all self-care activities."

3/ Data from an eight county HSA region.

4/ Data from residents in Michigan nursing homes. Classification of impairment levels varied from those in the table. "Unimpaired - mildly" impaired data taken from category titled "needs assistance." "Generally - totally" impaired data comes from the group who are "completely dependent."

5/ Data from the Cleveland Data Base.

- Second, the risk factors associated with institutional placement are not clearly enough defined to allow for the targeting of prevention services to only those people at high risk of institutionalization. As a result, under this strategy, the states may increase their service base and their aggregate costs.

OPTION 4: INCREASING THE SHARE OF EXPENSES ASSUMED BY FAMILIES

There are two ways to increase the share of long term care costs borne by families: one is to encourage families to provide this care themselves in the community and thus avoid or delay institutionalization; the other is to encourage or require families to pay for care for institutionalized relatives. Following a brief review of how much families now contribute to the care of the elderly both in and out of institutions, each of these options is discussed below.

What is the Current Level of Assistance that Families are Providing?

Families now provide by far the largest share of services to the elderly in addition to making significant financial contributions to their elderly relatives. An estimated 60 to 80 percent of all long term care services are provided by families.[18,22,123,127] The services range from personal services to transportation services to meal preparation, as illustrated by a study in Cleveland presented in Exhibit 7.

In addition to supporting family members in the community, families provide financial assistance to their institutionalized relatives. Personal income and family support are the primary sources of nursing home payment (38.4%) and are larger than the amounts paid by Medicaid. While the exact breakdown between family assistance and personal income is unknown, one study suggested that family contributions account for 11% of all sources of support for elderly people in nursing homes.[39]

EXHIBIT 7

SOURCES OF ASSISTANCE FOR ELDERLY PEOPLE IN CLEVELAND

	SOURCE			
	Family/Friends	Agency	Both	Total
Home Help Services				
Transportation	60%	3%	5%	68%
Personal Care	56%	1%	1%	58%
Homemaker	20%	5%	1%	26%
Administrative and legal	15%	7%	1%	23%
Meal Preparation	13%	8%	1%	22%
Continuous Supervision	6%	1%	1%	8%
Financial Assistance				
General Financial	2%	7%	-	9%
Housing	12%	10%	-	22%
Groceries and Food Stamps	7%	8%	-	15%

Source: General Accounting Office,
The Well-Being of Older People in Cleveland, Ohio, 1977.

It is commonly believed that families provide fewer services and less financial support now than they once did. This notion is based on a vision of the past which includes multi-generational extended family households where the elderly lived productively and were cared for and supported until death. There is little evidence that this vision was ever accurate across all classes.[102,123]

Multi-generational households have largely been a result of economic necessity throughout American history. They have increased during times of depression and have occurred in greater numbers among poor people. As improving economic conditions permit, working families have established nuclear family households. While economic circumstances of working families may once have encouraged multi-generational households, in more recent years job mobility has led many families to live at greater distances from their parents and in smaller homes. This dispersion may somewhat reduce the extent to which the impaired obtain services from their families, although there is evidence that some of those who become impaired move back to the areas in which their families live.

Other changes may have a stronger effect on the amount of care provided by families.[123,127] Personal care has traditionally been provided by women not employed outside the home, primarily wives and daughters.[18,127] The increased divorce rate and the increasing difference in life expectancy between men and women (combined with the fact that husbands are usually older than theire wives) has increased the number of single elderly who are primarily women, without sources of informal support. In addition, as women enter the work force in increasing numbers, it is more difficult for daughters to provide services to their elderly parents. Because people are living longer and developing chronic conditions requiring regular care later, children who might be expected to support their parents increasingly

are elderly as well. They face economic and health problems of their own which may interfere with their ability to care for their parents. Yet in spite of all these factors making family care more difficult, it appears that government services and financing for the elderly have merely kept pace with increasing needs rather than replaced family provided functional care.[69,123]

Can Programs be Developed to Increase the Care Provided by Families To Non-Institutionalized Relatives?

Several states have begun exploring policies designed to encourage family-based long term care. The basis for a family policy is the belief that the current reimbursement and service systems create obstacles for families in caring for their elderly relatives in the community and create strong incentives for institutionalizing the elderly to shift the costs of their care to the state. These policies attempt to reverse the incentives to make it easier for families to assume responsibility for their relatives and thus decrease unnecessary institutionalization and provide significant cost savings for state programs.

Two kinds of programs have been proposed or discussed to encourage increased family care and avoid institutionalization. One is the provision of support services, such as day and respite care to families taking care of an elderly relative. The other is to give families financial incentives to provide services.

Service Assistance

The option of providing social services to families to ease the personal burden of caring for an elderly person is largely unexplored. Advocates of this approach most frequently mention day and respite care as needed services:

- Day Care. It is possible that day care will help families maintain their elderly relatives in the community. The research on adult day care programs indicate that they tend to serve people who have informal supports.[98,106,112,125]

- Respite Care. There is no research which examines the ability of respite care to ease the personal burden of caring for an elderly person to a sufficient extent to prevent institutionalization. The idea has intuitive appeal and, even without supporting research, is widely advocated.

Financial Incentives

Financial incentives, including direct payments and tax breaks for families providing care to elderly relatives, may also increase family provided care. California and several other states have experimented with direct payment programs which use Title XX funds to reimburse family members who provide chore/homemaker and medical care to their elderly relatives. According to one review of relevant literature on California, "Statewide, the number of family members providing attendent care numbers in the tens of thousands at an annual cost of tens of millions of dollars." Relatives are responsible for providing services to an estimated 16% of all Title XX beneficiaries in the state.[22]

The Title XX program has three operational components in California:

- County public welfare agencies directly hire someone to perform needed services.

- County public welfare agencies may contract with provider agencies to perform services.

- Title XX beneficiaries hire someone to perform needed services and, after submitting a time sheet, are awarded Title XX funds with which to pay their employees. This situation is the most widespread. Out of approximately 100,000 Title XX beneficiaries, an estimated 65,000 receive services in this way. Of these 65,000, approximately 25% hire their own relatives for average salaries of $200 a month.

Other states have implemented similar programs. The Michigan Adult Chore Service Program uses Title XX funds to pay relatives and other individuals to provide home maintenance and other non-nursing care to SSI eligible individuals. The Oklahoma "Non-Technical Medical Care in Own Home" portion of the state's Medicaid program pays neighbors, friends, or distant relatives to provide home services. An Alabama program operates under a different model, permitting welfare-eligible family members to operate adult day care centers in their own homes for a relative and a few non-relatives.[58]

The state of Oregon has just passed a law which will provide indirect incentives to families to provide financial support to their relatives. House Bill 22-28 provides a personal income tax deduction of the lower of $250 or 8% of expenses for food, clothing, medical or transportation related expenses incurred for the care of someone who:

- Is at least 60 years old.
- Has an annual income of less than $7,500.
- Is certified by the Department of Human Resources as eligible for Oregon's Project Independence (at high risk of institutionalization). (House Bill 22-28)

These programs may be spending state funds on services that would be provided without expenditure of public dollars. As was discussed previously, even without financial incentives, families provide 60 to 80% of long term care services and an unmeasured percentage of financial support. None of the programs identified has been evaluated to determine whether it has increased the services provided by family members or reduced the demand for either institutional or non-institutional services that might be funded by the state.

These financial incentive programs may have other social benefits. For example, many of the relatives being paid under the California program have low incomes so this program both delivers needed services to the aged and provides income assistance to poor people. Ironically, this very income assistance may result in substituting state monies for federal funds. Title XX funds are paid to low income people who are providing long term care to their relatives (most notably spouses). Program administrators claim that frequently this raises their income to a point where they become ineligible for SSI, which is federally funded (although there may be a state supplement). Yet, because California has surpassed its Federal cap for matching expenditures, all new Title XX expenditures are paid entirely out of state funds.

There is inadequate research to determine whether policies designed to increase family provided services are the least costly way for the states to encourage the use of non-institutional care. Further evaluation is needed on the effectiveness of current programs which subsidize families for the costs of services they provide and the ability of services, such as respite care, to increase their willingness to keep their relatives at home.

Can Programs be Developed to Increase Family Support for the Institutionalized Elderly?

Programs to encourage or require families to pay an increased share of costs for their institutionalized relatives do not appear very promising because the data indicates that they already may contribute to the limit of their financial ability and because calling upon limited additional resources may be legally and administratively cumbersome.

There are three types of family members who the state may approach for additional contributions: spouses, children, and other relatives. This last category cannot be legally required to provide financial support, so the feasibility of mandating contributions from them is not examined.

- Spouses. According to the Survey of Institionalized Persons, less than 7% of all nursing home residents are married. This immediately limits the potential for obtaining funds from this source. For those who are married, spouses are already contributing significantly to the cost of their spouses' institutional care. By one estimate, in 1976 spouses contributed a mean average of $2,025 a year for the cost of nursing home care, while their mean income was only $7,890.[22] By tapping spouses

for further financial contribution, the state would probably not generate long term savings. As was discussed in the previous chapter, elderly people whose spouses are institutionalized are themselves at high risk of institutionalization. The financial strain of financing a spouse's care might be severe enough to impoverish the individual so that he or she would not have the resources to care for him or herself. Thus, spouses seem an unpromising source of additional money.

- Children. Demographic trends are creating a situation in which there are a growing number of elderly whose children are themselves elderly and are, therefore, likely to have few resources.[22] Whereas in 1960, there were only 34 people over the age of 80 for every 100 people between the ages of 60 and 64, by 1990 there are expected to be 63 people over the age of 80 for every 100 people between the ages of 60 and 64.[89] In addition, there are legal obstacles to requiring financial support from children. Even if these could be addressed, defining support responsibilities for siblings with different incomes, geographic locations, and responsibilities to their own children and other elderly relatives would be extremely difficult. Thus, the legal and situational obstacles to mandating support from children also make them an unpromising source of funds.

The final issue considered here is asset shifting. There are anecdotal experiences that lead people to believe that families encourage their elderly relatives to shift their assets to their children in order to become eligible for Medicaid services. Because it imposes both an income test and an asset test, the Medicaid program itself may act to encourage this practice.

Unfortunately, this idea has not been adequately researched. One of the few discussions, The Treatment of Assets and Income from Assets in Income-Conditioned Government Benefit Programs, concludes that a "small, but not negligible" number of beneficiaries of publicly funded programs, including Medicaid and SSI, possess substantial wealth in the form of assets and, to become eligible for public programs, are transferring or underreporting their assets.[60] It should be noted that the authors based this conclusion on anecdotal information and "sparse data sets." As a result, estimates of the number of people who transfer or underreport their assets or the costs that these people transfer to federal and state government are not available.

Shifted assets are most likely to be in the form of real estate, savings accounts, and stock. A study could be made of real estate transfers by elderly persons applying for Medicaid by looking at local real estate transactions. Studies of bank accounts and stock transfers might also be undertaken, but could present significant legal and logistical obstacles.

Before designing or carrying out elaborate asset transfer studies, it would be useful to examine basic data on the distribution of assets by age and other factors in order to determine whether such research is likely to produce useful results. For example, if fewer than 10% of the population over 50 or 60 hold assets of $20,000, the study may not be worthwhile because legislation and administration of a program to prevent asset shifting by such a small percent of the population is unlikely to be cost effective. Indeed, the administrative costs of a program to police asset transfers may be very high and should be carefully balanced against expected savings.[22]

OPTION 5: REDUCING INTERMEDIATE CARE FUNDED BY THE STATE

As a result of the financial squeeze imposed by escalating Medicaid costs, some states are considering a strategy which attempts to cut costs by reducing the care they fund at intermediate care facilities. This service has been mentioned because it is a substantial benefit yet an optional service. States may consider two approaches to this option:

- Abolishing the benefit either completely or for specific levels of ICF care, but seeking to replace critical services for the affected population with community-based alternatives.

- Simply discontinuing the benefit without any attempt to expand alternative services.

This section reviews the cost and social implications of these strategies.

Is Intermediate Care Needed by People in these Facilities?

The discussion of Option 1 in this chapter reviewed the literature examining inappropriate utilization of nursing homes to provide an indication of the extent to which there were clients who could be cared for in the community. The literature suggested that 20-40% of the population in intermediate care facilities do not need the level or intensity of services which is provided in these facilities. This is a wide range and the reasons for it are not clear. Among the possible causes are:

- Differences in the assessment instruments and standards used by researchers.

- Differences in community characteristics that produce different patterns of treatment and placement. These include nursing home and hospital bed supply, the availability of community services, and utilization review and preadmission screening practices.

Many of those who are inappropriately placed in intermediate care facilities do not require the constant supervision that is characteristic of ICFs or the type of services which they provide care above the level of room and board but below that of skilled nursing facilities or hospitals. Instead these people could be cared for in community settings if non-institutional services were available.[3,79] According to the research, the remaining residents of ICFs (60-80%) do require ICF level services. For these people, ICF level care is the least intense level of care which is appropriate.

What Preparations Would the State Need to Make to Prepare for a Reduction in Intermediate Care?

The research indicates that people who are inappropriately placed in institutions often cannot live in the community without a variety of supportive services, including at times, personal care, chore/homemaker services, and occasional medical services.

Housing would be needed for people who would be deinstitutionalized as a result of this program. For those who in the future would be unable to enter ICFs as a result of the program, if the loss of their current home was a precipitating factor, alternative housing would also be required. For both groups, some health care and other support would be needed.[13,79,90]

Has Any State had Experience Eliminating ICF Level Care?

As part of an 1115 waiver project approved by the Health Care Financing Administration (HCFA) on March 1, 1980, the state of Texas eliminated reimbursement for the lowest level of ICF institutional care previously reimbursed by the Medicaid program. While people in nursing homes continued to be eligible for institutional care, new applicants for the lowest level of ICF care were directed to either a higher level of ICF care (newly defined) or community-based services. Some efforts at deinstitutionalizing those in nursing homes were also to be made. In order to care for the affected population, the state attempted to expand the supply of community-based services. As well as providing a variety of services under Title XX and primary home care under Title XIX (with expanded eligibility for the medically needy), the state is currently exploring three new non-institutional options in several sites:

- Personal care homes which are based on the domiciliary care model.

- Emergency response systems whereby elderly people are supplied with "beepers" which allow them to call for emergency assistance.

- Respite care financing.

The state administrators of the program are, for the most part, satisfied with it. They have suggested several areas where problems have occurred, however:

- Non-institutional services are not uniformally available across the state.

- Despite political support for the project by the governor's office and the legislature, initial public reaction to the project was unfavorable. The press, the nursing home industry and community activist groups opposed the program.

An oversight in the design of the program fueled these groups' opposition in the program's early months. During the first few months of the program's operation, medically needy people in SNFs and high level ICFs who had their level of care reviewed and downgraded to low level ICF care, became ineligible for Medicaid assistance rather than being considered part of the population eligible for continued institutional care. The plight of these people received considerable press attention that resulted in bad publicity for the program. The situation was later corrected.

As part of the waiver agreement, the state is committed to an ongoing evaluation of the project. The first of these evaluations was completed in March, 1981. In addition, the federal government is performing an independent review. Among those factors covered by both sets of evaluations are:

- The number of people averted from institutions and deinstiutionalized as a result of the program.

- The types of services that are being delivered to these people.

- The cost savings accrued by the program.

What are the Cost Implications of This Strategy?

There is limited evidence on which to assess the cost implications of this strategy. The evidence that exists, however, suggests that it may not save the state money. Rather, it may shift costs among programs. By abolishing lower level intermediate care and replacing this care with other services, aggregate costs may decrease, but state liabilities may also increase. In Texas, for example, one of the major options which the state is pursuing as an alternative to lower level ICF care is personal care facilities. Although in Texas such facilities are less expensive than ICFs, their costs generally exceed monthly Social Security and SSI payments and no other federal cost sharing is available to cover this gap. It may be financed entirely by the state at a net higher cost.

One nursing home executive in Texas estimated that payments from Social Security and SSI benefits would be approximately $250 per patient month. Yet an additional $150 - $200 is needed per patient month to operate a personal care home. This compares with the state share for low-level ICFs after federal cost sharing and social security offsets are taken into account.

As part of the Texas evaluation, it is expected that the relative costliness of alternative care settings, including domiciliary care, will be examined.

A state could choose to place a ceiling on reimbursement of alternative services at a level that reflects the amount of support available from federal sources or the maximum budget exposure the state is prepared to accept. It should be realized, however, that

this may have a severe impact on the availability of alternatives (as providers leave the system because of inadequate return) and the quality and effectiveness of care (as providers scale down their services to reflect the funds made available to them).

It should also be noted that a strategy that relies on shifting patients from ICFs to domiciliary care facilities or boarding homes can increase the problems of policing the quality of care since it would increase the number of facilities being monitored, increase the number of small facilities (as boarding homes tend to have fewer beds than nursing facilities), and concentrate care into types of facilities for which few standards currently exist. Quality of care in boarding houses has been reported as being a problem.[42]

Even if intermediate care is terminated without the addition of non-institutional services, aggregate cost savings may not be achieved. While no direct evidence for this is available, the effects of a restriction or abolition of ICF care may be estimated from reviewing the experience of localities where a tight supply of nursing home beds exists.

In New York, Connecticut, Washington, D.C., Massachusetts, California, and Chicago, the PSROs, hospital organizations, or state auditors have estimated that because an insufficient supply of nursing home beds exists, people are being cared for at unnecessarily high levels of care in acute care settings.

The New York State PSRO, for example, estimates that 4,400 people waited an average of 2-1/2 months in acute care facilities for nursing home placement. Hospital care for these people cost an average of $200 per day whereas nursing home beds would have cost an average of $50.

Similarly, the Connecticut Hospital Association estimates that people in hospitals waiting for placement in SNFs or ICFs increased state Medicaid costs by $3 million last year (44.5% of the extended days were from Medicaid patients or patients waiting for Medicaid certification).[29]

If the strategy of ending intermediate care were to shift a substantial portion of these clients into hospitals rather than onto private resources in their communities, the aggregate cost savings of the ICF nursing home closings may be offset by the increased costs of hospital care. A similar situation may develop with clients being redirected into skilled nursing facilities.

Yet, the impact of such back ups on state costs is not clear. Patients backed-up in hospitals who are certified as needing skilled level care are eligible for Medicare, which is financed entirely by the federal government. While these benefits run out (60 days of full coverage and 30 days of partial coverage for any episode of illness; 60 days of partial coverage under the lifetime reserve), Medicare recognizes bad debt as an expense of those for whom Medicare was the primary payer. As a result, even when a patient's eligiblity runs out, a hospital may be able to recover the cost of his care from federal funds.

Thus, if ICF level patients are backed-up in hospitals but are certified as needing SNF level care, the states may assume very little responsibility for the cost of their care. In at least one area, there is evidence that this is happening. The Finger Lakes Health Systems Agency of New York reports that 93.2% of all hospital patient days attributed to back-up were paid for by Medicare. Furthermore, according to the HSA, some of these patients, despite their SNF classifications might be appropriately care for at the ICF level.[38] If displaced ICF level patients were to end up in SNFs, while Medicare might not cover these patients, this could lead to further Medicare financed backup into the hospital system.

In conclusion, abolishing ICF services without replacing the care delivered by these institutions with community or home-based services might have the following implications:

- Significant hardships may be imposed on the people who have traditionally used this service:
  - -- The 60-80% of ICF residents for whom intermediate care represents an appropriate placement.
  - -- The 20-40% of ICF residents who may be cared for in the community but need supportive services to function adequately.

- Increased aggregate costs may arise as some clients obtain care at higher levels and greater cost than is necessary. This may occur in two ways:
  - -- In a step progression whereby there are people who are cared for at each level of care who could be cared for at the next lowest level of care (i.e., hospitals serving SNF patients, SNFs serving ICF patients).

-- Across the board so that the profile of patients who are inappropriately placed in hospitals are similar to those who are inappropriately placed in SNFs.

Restricting or abolishing ICF level care and attempting to replace it with non-institutional services might have the following implications:

- As a deinstitutionalization strategy, it requires developing housing and supportive services for this population. The difficulties of providing these, especially housing, for just a portion of the ICF population was described in Option 1. A larger number to be moved out will intensify these problems.

- As a diversion strategy, it has the same potential as the diversion strategy described in Option 2 of this chapter. Since the costs of community-based care increase with client functional impairment, the costs may be as high or higher than institutional care for the 60 - 80% of present ICF residents who are appropriately placed. In addition, some of these potential ICF users may be diverted to SNF or hospital care, at much higher cost. If considered at all, partial discontinuance of the ICF benefit for the lowest levels of ICF care appears to be a sounder approach than complete abolition.

CHAPTER THREE
SOME MAJOR UNANSWERED QUESTIONS

The review of research and information on long term care and the needs of the elderly has disclosed a large number of unanswered questions and limited information upon which to analyze policy. A comprehensive research agenda in this area would be extremely long. There are, however, seven research areas that are particularly important because additional information could influence state policy decisions. These seven areas are briefly described in this chapter.

Factors Influencing the Use of Publicly Funded Services

A large portion of the long term care services in this country are provided by families and friends or purchased privately. The most significant concern (after financing) in planning for the new services is whether public provision of a service will reduce the level of private effort and simply shift the support of these services to the public sector with little gain in improving quality or providing care for those not currently receiving it from any source. The review of current patterns of family support suggests this concern may be overstated, but that it has some validity, as some community-based services are being used extensively by individuals with other social ties.

Since this is such a critical issue in program design, more research is essential. In particular, information is needed on:

- The rates of substitution of public for private services and the factors influencing these rates.

- The factors that influence the use rates of services. The nature of the interaction among levels of impairment, social supports, and income.

With respect to institutional services and institutionalization, more information is needed on:

- The factors influencing family decisions to seek institutionalization, and the influence of available community-based services on those decisions.

- The asset transfer problem, including its scope, the conditions or circumstances under which transfers are made, and the level of support from families proceeding and following transfer.

Patients in Intermediate Care Facilities

Several options, if effectively implemented, would reduce the current ICF population. Those emptied beds are likely to be refilled, but currently it is not known whether the new clients would be released from SNF and hospital beds or community-based settings. States need better information on patient transfer patterns and insights into the types of interventions that can encourage transfers from more costly settings.

Performance of Individual Services

Three types of studies should be carried out to obtain a better understanding of the potential role of alternative services in the long term care system:

- There is a need for better models of the costs of services in alternative settings. It is known that home health care, for example, can cost more than institutional care for some clients, less for others. Models are needed that identify the variables influencing these costs and allow states to estimate the appropriate mix of institutional and non-institutional settings in terms of minimizing cost.

- One cost modelling study that is particularly important, given the interest in reducing intermediate care, is an analysis of the relative costs and substitutability of ICFs, domiciliary care facilities, and congregate housing.

- Further evaluation needs to be done of almost all long term care services. Several services or approaches to care, however, merit special attention because they are being strongly advocated while there is little data. These include:

  -- Respite care

  -- Other programs to provide families with financial or service support

  -- Nutrition programs

  -- Housing programs, in particular focussing on their roles (1) as a housing alternative for institutionalization and (2) in reducing future levels of impairment or need for institutionalization.

Case Management

More research is needed to assess how these agencies influence the use of services in the communities in which they operate and the role that they play in family decision making.

The Socially Isolated

The review of individual services suggests that currently long term care programs have not served a disproportionate number of the socially isolated, i.e., those with fewer sources of privately contributed assistance. Research should be pursued which identifies models of service organization and outreach that more effectively reaches this group.

Control of Program Growth

One of the major areas of concern for state health policy-makers is the fear of a runaway program budget. New initiatives in particular are deferred or abandoned because of this concern. What state officials require is either methodologies that will allow them to accurately predict program utilization and costs or demonstrated program management techniques that assure that utilization and costs can be controlled. Research can help identify or develop both of these.

Changes in Health Manpower

The number and mix of health professionals in the country are changing. Increasingly, a physician surplus is predicted. These patterns might have several effects on long term care, including increasing client access to medical services or emphasizing the medical over the social model of care. The potential effects of changes in manpower need to be estimated and evaluated.

Program Administration

One of the goals for the report as it was originally organized was to provide an indication of the critical administrative factors in program performance in the long term care field. That effort had to be significantly reduced because there has been almost no study of the

administrative and organizational factors that enable a program to succeed in one location while another with similar goals and overall strategy fails in a different setting. Much greater effort needs to be applied to the development of this type of information and its transfer to the state and local program managers and policy-makers.

REFERENCES

The following references were used in the preparation of this synthesis and in the accompanying synthesis Expanding Long Term Care Efforts: Options and Issues in State Program Design. An asterisk (*) before the author's name indicates that the material covered by the reference is particularly relevant to the issues addressed by the two syntheses. An abstract of these documents has been prepared and appears in Long Term Care: Options and Issues in State Programs: A Bibliography.

1.* Applebaum, Robert; Seidl, Fredrick W.; Austin, Carol D., "The Wisconsin Community Care Organization: Preliminary Findings from the Milwaukee Experiment," The Gerontologist Vol. 20, No. 3, 1980, 350-355.

2. Applied Management Sciences, Analysis of Incentive Reimbursement System for Health Care and Long Term Care Services Provided to the Elderly and Long Term Disabled: Development and Validation of a Patient Assessment Index, Interim Report No. 3, Contract No. HEW-100-76, 0029, Silver Spring, Maryland, January 1976.

3.* Baltay, Maureen, Long Term Care for the Elderly and Disabled, Congressional Budget Office, February, 1977.

4.* Baltay, Maureen; Trapnell, Gordon, Long Term Care: Actuarial Cost Estimates, A Technical Analysis Paper. Congressional Budget Office, August, 1977.

5.* Barney, Jane Lockwood, The Well-Being Report, Institute of Gerontology: The University of Michigan-Wayne State University, 1975.

6.* Barney, Jane Lockwood, Patients in Michigan Nursing Homes: Who Are They: How Are They? Why Are They There? Detroit, Michigan: Institute of Gerontology, 1973.

7. Beattie, Robert T.; Jordan, Harmon S.,
"A Preliminary Analysis of a Survey of Massachusetts Hospital Patients Who Were Ready for Discharge and Awaiting Placement in Other Facilities," Massachusetts' Department of Health mimeo, April 11, 1975.

8.* Bell, William G.,
"Community Care for the Elderly: An Alternative to Institutionalization," The Gerontologist, Autumn 1973. 394-354.

9. Berg, Robert L.; Browning, Francis E.; Hill, John G.; Wenkert, Walter,
"Assessing the Health Care Needs of the Aged," Health Services Research, Vol. 5, 1970. 36-59.

10. Bishop, Christine,
"Nursing Home Cost Studies and Reimbursement Issues," Health Care Financing Review, Vol. 1, No. 4, Spring 1980.

11.* Bishop, Christine; Plough, Alonzo; Willemain, Thomas,
"Nursing Home Levels of Care: Problems and Alternatives," Health Care Financing Review, Vol. 2, No. 2, Fall 1980.

12. Blenkner, Margaret,
"Environmental Change and the Aging Individual," Gerontologist, No. 7, 1967. 101-105.

13.* Booz, Allen & Hamilton,
Summary of the Major Findings of the Long Term Care Study, Illinois Department on Aging, Springfield, Illinois, July 1975.

14.* Borup, Jerry H.; Gallego, Daniel T.; Hefferman, Pamela G.,
"Relocation and its Effect on Mortality," The Gerontologist, Vol. 19, No. 2, 1979. 135-140.

15.* Bourestom, Norman; Tars, Sandra,
"Alternations in Life Patterns Following Nursing Home Relocations," The Gerontologist, December 1979.

16.* Brickner, Philip W.; Scharer, Linda Keen,
"Hospital Provides Home Care for Elderly at One-Half Nursing Home Cost," Forum, Vol. 1, No. 2, November - December 1977. 7-12.

17.* Brickner, Philip W.; Janeski, James F.; Rich, Gloria; Duque, Sister Teresita; Starita, Laura; LaRocco, Richard; Flannery, Thomas; Werlin, Steven,
"Home Maintenance for the Home-bound Aged: A Pilot Program in New York City," The Gerontologist, Vol. 16, No. 1, Pt. 1, 1976. 25-29.

18.* Brody, Stanley J.; Poulshock, S. Walter; Masciocchi, Carla F., "The Family Caring Unit: A Major Consideration in the Long Term Support System," The Gerontologist, Vol. 18, No. 6, 1978. 556-561.

19. Burton, Richard M.; Damon, William W.; Dellinger, David C.; Erickson, Douglas J.; Peterson, David W., "Nursing Home Cost and Care: An Investigation of Alternatives," Durham, North Carolina, Center for the Study of Aging and Human Development, Duke University Medical Center, mimeo, July 8, 1974.

20.* Butler, Lewis; Newacheck, Paul, "Health and Social Factors Relevant to Long Term Care Policy: A Paper prepared for the Symposium on Long Term Care Policy, Williamsburg, Virginia, June 11-13, 1980." Convened by the Center for the Study of Welfare Policy, University of Chicago, with support from the Administration on Aging, U.S. Department of Health and Human Services.

21. Callahan, James J., "Single Agency Option for Long Term Care," in Reforming the Long Term Care System: Financial and Organizational Options, Stanley S. Wallack and James Callahan (editors), Lexington, Mass: D.C. Heath and Company, 1981.

22.* Callahan, James J. Jr.; Diamond, Lawrence D.; Giele, Janet Z.; Morris, Robert, "Responsibilities of Families for their Severely Disabled Elders," Health Care Financing Review, Winter 1980.

23.* Callahan, James J. Jr., Delivery of Services to Persons with Long Term Care Needs, Levinson Policy Institute, University Health Policy Center, Brandeis University, October 1979.

24. Carp, Francis M., "The Concept and Role of Congregate Housing for Older People," in Congregate Housing for Older People: An Urgent Need, A Growing Demand, Donahue, Wilma; Thompson, Marie McGuire; Curren, D.J. (editors), U.S. Department of Health, Education and Welfare, Administration on Aging, 1977.

25. Center for the Study of Welfare Policy, University of Chicago, "Current Housing Arrangements for Those in Need of Long Term Care," undated draft.

26. Center for the Study of Welfare Policy, University of Chicago, "Housing and Supportive Services for Long Term Care Clients," draft, August 29, 1980.

27.* Cohen, Donald; Shaw, David; Brumhofer, Margaret; Janney, Richard, "Transfer Trauma Study." The State University of New York at Albany, School of Social Welfare, July 6, 1979.

28. Conly, Sonia, Critical Review of Research on Long Term Care Alternatives, U.S. Department of Health, Education, and Welfare/Project Share, 1977.

29. Connecticut Hospital Association, CHA Reports, No. 2, January 1980.

30. Davis, John W.; Gibbon, Marilyn J., "An Areawide Examination of Nursing Home Use, Misuse and Nonuse," American Journal of Public Health, Vol. 61, 1971. 1143-1155.

31. Delmarva Foundation for Medical Care, "Patients in Nursing Homes with Less than Comprehensive Nursing Need Compared to Hospital Patients Waiting for Nursing Home Beds," unpublished memo.

32. Diamond, Larry; Berman, David E., "The Social/Health Maintenance Organization: A Single Entry, Prepaid, Long-Term Care Delivery System," in Reforming the Long Term Care System: Financial and Organizational Options, Stanley S. Wallack and James Callahan (editors), Lexington, Mass: D.C. Heath and Company, 1981.

33.* Doherty, Neville J. G.; Hicks, Barbara C., "The Use of Cost-Effectiveness Analysis in Geriatric Day Care," The Gerontologist, October 1975. 412-417.

34. Donahue, Wilma; Thompson, Marie McGuire; Curren, D.J. (editors), Congregate Housing for Older People: An Urgent Need, A Growing Demand, U.S. Department of Health, Education, and Welfare/Administration on Aging, 1977.

35.* Dunlop, Burton D., "Expanded Home-Based Care for the Impaired Elderly: Solution or Pipe Dream?" American Journal of Public Health, Vol. 70, No. 5, May 1980. 514-519.

36.* Eggert, Gerald M.; Bowlyow, Joyce E.; Nichols, Carol W., "Gaining Control of the Long Term Care System: First Returns From the ACCESS Experiment," The Gerontologist, Vol. 20, No. 3, 1980. 356-363.

37. Fillenbaum, G., "Social Context and Self-Assessments of Health Among the Elderly," Journal of Health and Social Behavior, March 1979. 45-51.

38. Finger Lakes Health Systems Agency,
Task Force Report on the Hospital Back-Up of Long Term Care Patients, Rochester, New York, November 1980.

39.* General Accounting Office,
Entering a Nursing Home -- Costly Implications for Medicaid and the Elderly, 1979.

40.* General Accounting Office,
"The Potential Need for and Cost of Congregate Housing for Older People," Memorandum to the Chairman and the Ranking Minority Member, Special Committee on Aging, U.S. Senate, October 1979.

41. General Accounting Office,
Home Health Care Services -- Tighter Fiscal Controls Needed, 1979.

42. General Accounting Office,
Identifying Boarding Homes Housing the Needy Aged, Blind, and Disabled: A Major Step Toward Resolving a National Problem, 1979.

43. General Accounting Office,
State Programs for Delivering Title XX Social Services to Supplemental Security Income Beneficiaries Can be Improved, 1979.

44. General Accounting Office,
"The Conditions and Needs of People 75 Years Old and Older," Memorandum prepared for the Chairman of the House Select Committee on Aging, October 15, 1979.

45.* General Accounting Office,
Actions Needed to Improve the Nutrition Program for the Elderly, 1978.

46.* General Accounting Office,
Home Health -- The Need for a National Policy to Better Provide for the Elderly, 1977.

47.* General Accounting Office,
The Well-Being of Older People in Cleveland, Ohio, 1977.

48. Gentry, John T.; Curlin, Victor R.,
"The Illinois Long Term Care Classification Instrument: Use Experience Within the New York City Medicaid Program," Medical Section, Bureau of Health Care Services, New York City Department of Health, May 8, 1975.

49.* Greenberg, Jay N.; Doth, David; Johnson, Allan N.; Austin, Carol,
A Comparative Study of Long Term Care Demonstration Projects: Lessons for Future Inquiry, Center for Health Research, University of Minnesota, March, 1980.

50. Greenberg, Jay; Pollak, William,
"Cost Estimation and Long-Term Care Policy: Problems in Forecasting the Undefined," unpublished, 1980.

51. Greenberg, Jay,
"The Costs of In-Home Services," in A Planning Study of Services to Non-Institutionalized Older Persons in Minnesota, Nancy Anderson (editor), Governor's Council on Aging, State of Minnesota, Minneapolis, Minnesota, 1974.

52. Gruenberg, Leonard W.; Pillemar, Karl,
"Disability Allowance for Long Term Care," in Reforming the Long Term Care System: Financial and Organizational Options, Stanley S. Wallack and James Callahan (editors), Lexington, Mass: D.C. Heath and Company, 1981.

53. Hammil, Charlotte,
"The Physical Health Model of Day Care," in Daycare for Older Adults: A Conference Report, Eric Pfeiffer (editor), Center for the Study of Aging and Human Development, Duke University, 1977.

54.* Hammond, John,
"Home Health Care Cost Effectiveness: An Overview of the Literature," Public Health Reports, Vol. 94, No. 4, 1979. 305-311.

55. Heumann, Leonard F.,
"Estimating the Local Need for Elderly Congregate Housing," The Gerontologist Vol. 16, No. 5, 1976. 397-403.

56.* Hodgson, Joseph H., Jr.; Quinn, Joan L.,
"The Impact of the Triage Health Care Delivery System Upon Client Morale, Independent Living and the Cost of Care," The Gerontologist, Volume 20, No. 3, 1980. 364-371.

57. Holmes, Douglas; Hudson, Edwin M.; Steinbeck, Leonard; Zitin, Daniel,
Excerpt Summary of a National Study of Levels of Care in Intermediate Care Facilities (ICFs), New York: Community Research Application, 1976.

58.* Humm-Delgado, Denise; Morris, Robert,
Family Policy and the Disabled: Examples of Family Payments for Long Term Disability, Levinson Policy Institute, The Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, September 1976.

59.* Illinois Department on Aging,
Comprehensive Alternative Care Program for the Elderly: Evaluation Report, Volume III, September 1978.

60. The Institute for Research on Poverty,
The Treatment of Assets and Income for Assets in Income conditioned Government Benefit Programs, Federal Council on the Aging, September 1977.

61. Interagency Statistical Committee on Long-Term Care for the Elderly,
Data Coverage of the Functionally Limited Elderly, U.S. Office of Management and Budget/Human Resources, Veterans, and Labor Special Studies Division, 1980.

62. Joe, Tom; Meltzer, Judith,
Policies and Strategies for Long-Term Care, Health Policy Program, School of Medicine, University of Calfornia, 1976.

63.* Kane, Robert L.; Rosalie A.,
"Alternatives to Institutional Care of the Elderly: Beyond the Dichotomy," The Gerontologist, Vol. 20, No. 3, 1980. 249-258.

64. Kaplan, Jerome,
"Goals of Daycare: Restoration of Function and Maintenance and Prevention of Decline," in Daycare for Older Adults: A Conference Report, Eric Pfeiffer (editor), Center for the Study of Aging and Human Development, Duke University, 1977.

65.* Kastenbaum, Robert; Candy, Sandra E.,
"The 4% Fallacy: A Methodological and Empirical Critique of Extended Care Facility Population Statistics," International Journal on Aging and Human Development, Vol. 4., No. 1, 1973.

66. Killian, E.C.,
"Effect of Geriatric Transfers on Mortality Rates," Social Work, January 1970.

67. Kurowski, Bettina; Breed, Linda,
A Synthesis of Research on Client Needs Assessment and Quality Assurance Programs in Long-Term Care, Western Interstate Commission for Higher Education, 1981.

68.* Kurowski, Bettina; Schlenker, Robert; Tricarico, Gerri,
Applied Research in Home Health Services, Volume II: Cost Per Episode, Center for Health Services Research, University of Colorado Medical Center, March 1979.

69.* Kutza, Elizabeth A.,
Allocating Long Term Care Services: The Policy Puzzle of Who Should Be Served, School of Social Service Administration, University of Chicago, February 1980.

70.* Kutza, Elizabeth,
"Eligibility Considerations in the Provision of Long Term Care Services for a Coordinated Approach to the Design and Development of Long Term Care Projects," The Center for the Study of Welfare Policy, the University of Chicago, May 1979.

71.* LaVor, Judith,
From Simple Idea to Complex Execution: Home Health Services Under Titles XVIII, XIX, and XX, draft of DHEW/HCFA Report to the Congress pursuant to P.L. 95-142, 1978.

72.* LaVor, Judith; Callender, Marie,
"Home Health Cost Effectiveness. What Are We Measuring?" Medical Care, Vol. XIX, No. 10, October 1976. 866-872.

73.* Lawton, M. Powell,
"Institutions and Alternatives for Older People," Health and Social Work, Vol. 3, No. 2, May 1978.

74. Lewin and Associates,
The Washington Home: A Program for the 80's, unpublished, 1980.

75. Lipscomb, Joseph; Raskin, Ira E.; Eichenholz, Joseph,
"The Use of Marginal Cost Estimates in Hospital Cost Containment Policy," in Hospital Cost Containment: Selected Notes for Future Policy, Zubkoff, Michael; Raskin, Ira E.; Hanft, Ruth (editors) New York: Prodist, 1978.

76.* Lombardi, Tarky,
"New York's 'Nursing Home Without Walls' Program," Health Care Cost Containment Project, National Conference of State Legislatures, May 1980.

77.* Lorenze, Edward J.; Hamill, Charlotte M.; Oliver, Robert C.,
"The Day Hospital: An Alternative to Institutional Care," Journal of American Geriatrics Society, Vol. XXII., No. 7, July 1974. 316-320.

78. Maddox, George,
"Focus: Day Care," in Daycare for Older Adults: A Conference Report, Eric Pfeiffer (editor), Center for the Study of Aging and Human Development, Duke University, 1977.

79.* Malafronte, Donald; Moses, Howard H.; Bronson, Rhona M.; Kunreuther,
Carol A.; Breyer, Peter R.,
"Appropriateness of Long-Term Care Placement: A Study of Long-Term Care Patients in the New Jersey Medicaid Program," in The Medicaid Experience, Allen D. Spiegel (editor), Aspen Systems Corporation, Germantown, Maryland, 1979.

80. Markus, Elliot; Blenkner, Margaret; Bloom, Martin; Downs, Thomas, "Some Factors on their Association with Post-Relocation Mortality Among Institutionalized Aged Persons." Journal of Gerontology, 1972.

81.* Masciocchi, Carla; Poulshock, S. Walter; Brody, Stanley J., "Impairment Levels of Ill Elderly: Institutional and Community Perspective," Presented at the 32nd Annual Scientific Meeting of the Gerontological Society, Washington, D.C., November 25-29, 1979.

82. Massachusetts Department of Public Health studies cited in Robert Morris, Alternatives to Nursing Home Care: A Proposal, prepared for use by the Special Committee on Aging, United States Senate, Washington, D.C., U.S. Government Printing Office, October 1971.

83.* Matlack, David R., "The Case for Geriatric Day Hospitals," The Gerontologist, April 1974. 103-113.

84.* Meltzer, Judith; Farrow, Frank, Federal Policy Directions in Long Term Care, Center for the Study of Welfare Policy, University of Chicago, August 1980.

85. Miller, Winston R.; Hurley, Sandra J.; Wharton, Elaine, "External Peer Review of Skilled Nursing Care in Minnesota," American Journal of Public Health, Vol. 66, 1976. 278-283.

86. Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1974-1975, Rochester, New York, 1975.

87. Monroe County Health Council, Survey of the Need for Inpatient Beds in Monroe County, 1969-1970, Rochester, New York, 1970, cited in T. Franklin Williams et al. "Appropriate Placement of the Chronically Ill and Aged," Journal of the American Medical Association, December 10, 1973.

88. Morrison, Malcolm, "SSI Recipients in Medicaid Institutions," Social Security Bulletin, December 1978.

89. The National Journal with the Xerox Corporation, National Journal Issues Book: The Economics of Aging, 1978.

90.* New York State Department of Social Services and Office of Health Systems Management, New York State Long Term Home Health Care Program, February 1980.

91.* Newcomer, Robert J. and Susan Ross; Gelwicks, Louis E., "Assessing the Need for Semi-Dependent Housing for the Elderly," The Gerontologist, Vol. 16, No. 2, 1976. 112-117.

92.* Palmore, Erdman, "Total Chance of Institutionalization Among the Aged," The Gerontologist, Vol. 16, No. 6, 1976. 504-507.

93. Paringer, Lynn; Bluck James; Feder, Judith; Holahan, John, Health Status and Use of Medical Services: Evidence on the Poor, the Black, and the Rural Elderly, The Urban Institute, 1979.

94.* Pegels, C. Carl, "Institutional vs. Noninstitutional Care for the Elderly," Journal of Health Politics Policy and Law, Vol. 5, No. 2, Summer 1980.

95.* Pfeiffer, Eric, (editor), Day Care for Older Adults: A Conference Report, Center for the Study of Aging and Human Development, Duke University, 1977.

96. Pollak, William, Expanding Health Benefits for the Elderly, Volume I: Long Term Care, The Urban Institute, 1979.

97. Quinn, Joan Litchfield, Triage, Inc.: An Alternative Approach to Care for the Elderly, 1974 - 1979, U.S. Department of Health, Education, and Welfare/National Center for Health Services Research with the Connecticut Department on Aging, 1979.

98. Rathbone-McCuan, Eloise, "Range and Scope of Daycare Clients," in Daycare for Older Adults: A Conference Report, Eric Pfeiffer (editor), Center for the Study of Aging and Human Development, Duke University, 1977.

99.* Sager, Alan, Learning the Home Care Needs of the Elderly: Patient, Family, and Professional Views of an Alternative to Institutionalization, Levinson Policy Institute, The Florence Heller School for Advanced Studies in Social Welfare, 1979.

100. Scanlon, William J., "A Theory of the Nursing Home Market," Inquiry, Spring 1980. 25-41.

101.* Scanlon, William; Difederico, Elaine; Stassen, Margaret, Long-Term Care: Current Experience and a Framework for Analysis, The Urban Institute, Washington, D.C., 1979.

102. Schorr, Alvin,
"... Thy Father and Thy Mother ...": A Second Look at Filial Responsibility and Family Policy, U.S. Department of Health and Human Services, SSA Publication No. 13-11953, July 1980.

103. Sherwood, Sylvia; Morris, John,
"Developing a Screening Instrument for Use by Local Housing Authorities in Determining the Need for Sheltered Housing Such as Highland Heights," unpublished, undated.

104.* Sherwood, Sylvia; Greer, David; Morris, John; Mor, Vincente,
The Highland Heights Story, Executive Summary, unpublished, 1973.

105.* Skellie, F. Albert; Coan, Ruth E.,
"Community-based Long Term Care and Mortality: Preliminary Findings of Georgia's Alternative Health Services Project," The Gerontologist, Vol. 20, No. 3, 1980.

106.* State of Connecticut, Department on Aging,
Adult Day Care in Connecticut: A Report to the General Assembly, September 1979.

107. State of Florida, Department of Health and Rehabilitative Services, Office of the Inspector General, Office of Evaluation,
Evaluation Report (Phase I): Florida's Community Care for the Elderly Program, 1981.

108. State of Florida, Department of Health and Rehabilitative Services, Office of the Inspector General, Office of Evaluation,
Nursing Home Evaluation Study, August 1980.

109.* State of Florida, Department of Health and Rehabilitative Services,
Program Planning, Office of Evaluation,
An Evaluation of Home Health Care Services in Florida, December 1978.

110.* State of Florida, Office of Evaluation, Program Planning and Development, Department of Health and Rehabilitative Services,
An Evaluation of Florida's Community Care for the Elderly Program, November 1978.

111.* Taber, Merlin A.; Anderson, Steve; Rogers, C. Jean,
"Implementing Community Care in Illinois: Issues of Cost and Targeting in a Statewide Program," The Gerontologist, Vol. 20, No. 3, 1980. 380-386.

112. Trager, Brahna,
Adult Day Health Care - A Conference Report, Department of Health, Education, and Welfare/National Center for Health Services Research, 1979.

113. Tynan, Eileen; Holub, Daniel; and Schlenker, Robert S.,
A Synthesis of Research on Nursing Home Reimbursement, Western Interstate Commission on Higher Education, 1981.

114. The Urban Institute,
The Interrelationships of Benefit Programs for the Elderly, Appendix II: Programs for Older Americans in Four States: A Case Study of Federal, State and Local Benefit Programs, Federal Council on the Aging, 1975.

115. U.S. Dept. of Health, Education, and Welfare, National Center for Health Statistics,
The National Nursing Home Survey: 1977 Summary for the United States, 1979.

116. U.S. Dept. of Health, Education, and Welfare, Social Security Administration Office of Research and Statistics,
Income of the Population 55 and Over, 1976, SSA Publication Number B-11865, December 1979.

117. U.S. Dept. of Health, Education, and Welfare, Deputy Assistant Secretary for Planning and Evaluation,
"Major Initiative on Long Term Care/Community Services Reform: Report of the Task Force," memorandum prepared for the Undersecretary of Health, Education, and Welfare, July 14, 1978.

118.* U.S. Department of Health, Education and Welfare,
Office of Human Development, Administration on Aging, Congregate Housing for Older People: An Urgent Need, A Growing Demand, DHEW Publication No. (OHD) 77-20284, 1977.

119. U.S. Dept. of Health, Education, and Welfare, Administration on Aging,
Evaluative Research on Social Programs for the Elderly, 1977.

120. U.S. Dept. of Health, Education, and Welfare, Public Health Service, Office of Long Term Care,
Long-Term Care Facility Improvements Study: Introductory Report, HEW Publication No. (OS) 76-50021, Rockville, Maryland July 1975.

121.* U.S. Department of Housing and Urban Development,
Office of Policy Development and Research, Division of Policy Studies, Housing for the Elderly and Handicapped: The Experience of the Section 202 Program from 1959 to 1977, January 1979.

122.* U.S. Department of Housing and Urban Development, Office of Policy Development and Research, Evaluation of the Effectiveness of Congregate Housing for the Elderly, prepared by Urban Systems Research and Engineering, Inc., Cambridge, Massachusetts, September 1976.

123.* U.S. House of Representatives, Subcommittee on Human Services of the Select Committee on Aging, Future Directions for Aging Policy: A Human Service Model Pub. No. 96-226, May 1980.

124.* U.S. Senate, Select Committee on Nutrition and Human Needs, The Homebound Elderly: The Need for a National Meals on Wheels Program, November 1976.

125. U.S. Senate, Special Committee on Aging, Adult Day Facilities for Treatment, Health Care, and Related Services: A Working Paper, 1976.

126. U.S. Senate, Special Committee on Aging, Congregate Housing for Older Adults, 1975.

127.* Vicente, Leticia, "A Model of Adult Children's Participation in the Care of Disabled Parents," an undated draft supported by a grant from the National Center for Health Services Research.

128.* Vicente, Leticia; Wiley, James A.; Carrington, R. Allen, "The Risk of Institutionalization Before Death," The Gerontologist, Vol. 19, No. 4, 1979.

129. The Virginia General Assembly, Joint Legislative Audit and Review Commission, Long Term Care in Virginia, 1978.

130. Vladeck, Bruce, Unloving Care: The Nursing Home Tragedy, New York: Basic Books, 1980.

131. Wallack, Stanley S.; Callahan, James, (editors), Reforming the Long Term Care System: Financial and Organizational Options, Lexington, Mass: D.C. Heath and Company, 1981.

132.* Weissert, William; Wan, Thomas; Livieratos, Barbara, Effects and Costs of Day Care and Homemaker Services for the Chronically Ill: A Randomized Experiment, National Center for Health Services Research Report Series, 1980.

133.* Weissert, William G.,
"Costs of Adult Day Care: A Comparison to Nursing Homes," Inquiry, Volume XV, March 1978. 10-19.

134.* Weissert, William G.,
"Two Models of Geriatric Day Care: Findings from a Comparative Study," The Gerontologist, Vol. 16, No. 3, October 1976. 420-427.

135. Willemain, Thomas,
"Nursing Home Levels of Care: Reimbursement of Resident Specific Costs," Health Care Financing Review, Vol. 2, No. 2, Fall 1980.

136. Willemain, Thomas R.,
"Beyond the GAO Cleveland Study: Client Selection for Home Care Services," Home Health Care Services Quarterly, Vol. 1, No. 3, Fall 1980.

137. Wolf, Leon,
"The Social Model of Daycare," in Daycare for Older Adults: A Conference Report, Eric Pfeiffer (editor), Center for the Study of Aging and Human Development, Duke University, 1977.

138. Zimmer, James G.,
"Characteristics of Patients and Care Provided in Health-Related and Skilled Nursing Facilities," Medical Care, Vol. 13, 1975. 992-1010.

139. Zweig, J.P.; Csank, J.Z.,
"Effect of Relocation on Chronically Ill Geriatric Patients of a Medical Unit: Mortality Rates," Journal of the American Geriatrics Society, March 1975.

APPENDIX

How Research was Identified and Assessed for this Report

This appendix outlines the process used to identify research included in this synthesis. It has two sections. The first discusses the literature search. The second section details the criteria used to evaluate the research selected.

The Literature Search

The litearture search concentrated on the research literature from 1975 to 1980 because of its applicability to current policy issues. For the preparation of this report, three categories of research were reviewed:

- Published Research (Studies appearing in journals and anthologies.) These were identified primarily through computerized systems, such as MEDLARS (Medical Literature Analysis and Retrival System), NTIS (National Technical Information Service), Project Share, and previously completed literature reviews.

- Unpublished Research (Work in progress or completed studies which have not yet been published.) To identify unpublished research, we contacted federal agencies, other organizations funding research in long term care, and university researchers who were known to be active in the field. When written documentation was not available, senior project personnel were interviewed.

- Reports of State Programs A large literature exists of reports done for state and local governments describing existing programs. Sometimes formal evaluations have been completed, but not always. As with the unpublished research, these materials were identified through contacts with state and local officials and academic researchers.

The Evaluation Process

When reviewing the research for this synthesis, two major criteria were considered:

- The reliability of the research results.
- The relevance of the research to the questions raised by the state officials who were consulted in planning the synthesis.

The following list of questions was used to guide the assessment of each study:*

1. What was the researcher trying to find out? How did that influence the usefulness of the research to the states' current situations?
2. How were things defined and measured?
   - Were the definitions clear and unambiguous?
   - Did the measures chosen truly reflect the underlying concepts? (e.g., How well does the presence of family within a 25-mile radius measure the availability of family support?)

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* Adapted from Donald T. Campbell and Julian C. Stanley's Experimental and Quasi-Experimental Designs for Research, Rand McNally College Publishing Company, Chicago, 1963.

3. How accurate was the data?

   - Was the data base adequate, consistent and reliable? Was there large random error or systematic bias?

   - Were the criteria used to classify information clear and uniformly applied? How was the subjectivity of the scores controlled? How much researcher judgment was involved?

4. How did the findings of this research compare with that of other research on the same subject?

   - If there were different results, why? Possible reasons considered were: different measures, groups studied, data sources, factors studied, time of study.

   - If the results were consistent with earlier research, did the studies have the same flaws? Multiple studies, each with the same flaws were judged less reliable than multiple studies, each of which was flawed differently.

5. Did the research take into account all the relevant factors? Were alternative explanations tested and rejected?

   - Was the impact of other factors analyzed? (e.g., Marital status when trying to assess the impact of impairment levels on the risk of institutionalization.)

   - Were there unique circumstances or historical reasons for the relationships found? (e.g., Many reviews of inappropriate utilization of nursing homes were undertaken before effective utilization review was in place.)

6. Was the analysis logical? Did the conclusions follow from the evidence? Did the evidence support the conclusion? Were "anomalies" in the data explained?

7. Did carrying out the research project itself influence the things being studied?

   - Were program changes made as a result of early results in the evaluation?

   - Did being surveyed make people more aware of conditions being studied?

8. Are the results dependent on the characteristics of the group studied or can they be generalized to other groups or settings? (e.g., Can the results of a study of Medicaid enrollees' utilization of home health services be used to predict the behavior of a private pay population?)

9. Was the sampling and sample size adequate?

   - Was self-selection important in determining which group each research subject fell into? Could this have influenced the results?

   - Could dropouts from the research sample or missing information on a small number of cases influence the findings?

10. Were the statistical techniques used appropriate?

Reviewed in light of the standards outlined above, every study examined had some flaws. A judgment had to be made on the seriousness of these flaws and on their impact on the potential usefulness of the

research (as characterized by the degree to which confidence could be placed on its findings).

These judgments were made on two bases. First, the study design of each study was assessed and the seriousness of the flaws was used to classify a study as substantially unreliable, weak, questionable, or strong.

Second, the research was considered in the context of other work on the same or related issues. Sometimes research projects in different areas complemented one another, lending credibility to the findings of each other. In other cases, the preponderance of the findings on an issue all supported the same conclusions. Where research findings conflicted, an attempt was made to reconcile the research by examining differences in research settings, measures or the method, or by choosing among alternative findings on the basis of what the strongest research disclosed.

Throughout the synthesis, comment is made on the conflicts or degree of support for the conclusions presented and on the degree of confidence that can be placed on them.